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ABSTRACT

This report presents outcome information concerning programs of the Colorado Division for Developmental Disabilities. Preliminary information outlines the legislative goals and the program evaluation process, which involves a longitudinal evaluation of service outcomes for a sample of adults receiving services, using the COPAR (Colorado Progress Assessment Review) instrument. In the summer of 1992, a stratified random sample of 781 adults receiving services were surveyed; due to sample attrition, 743 adults were surveyed in 1993. Findings are reported in detail for each question on the COPAR instrument and usually include overall results, comparison by service approach, comparison with the general population, and demographic data, as well as specifics. Findings concerning employment, day program, school, and other services are organized by the following categories: (1) satisfaction with services (in residential and supported living settings and in both integrated and segregated day services); (2) decision-making opportunities; (3) community inclusion; (4) community integrated employment (growth in the program, comparison of wages to minimum wage, and growth in average weekly hours of employment; growth in total earnings; and changes in community integration); (5) talents and personal goals; (6) relationships and a sense of belonging; (7) personal security; and (8) self respect. Also included are data on Colorado citizens' agreement with the Division's service values and their interactions with people having developmental disabilities. (Contains 31 references.) (DB)

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ED 391 343

A REPORT ON OUTCOMES OF SERVICES AND SUPPORTS FOR PERSONS WITH DEVELOPMENTAL DISABILITIES

October, 1994

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The Division would also like to recognize the creative energy dedicated by the following members of the COPAR Advisory Committee. This Committee was critical to the task of modifying the COPAR tool to better align it with the new legislative mission and with new values for people with developmental disabilities.

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There is an executive summary for this report which is entitled:

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INTRODUCTION

Great strides have been made towards achieving wide-spread recognition of new visions for people with developmental disabilities: Expectations that people are provided more opportunities for choice and control over their lives; to make friends; and to build ties with their community. Colorado is one of many states to adopt legislation which embodies these new outcomes. Additionally, new support models are being developed across the nation to implement these visions.

With the advent of new legislative goals and with new approaches to service delivery, important questions to ask and to attempt to answer are:

"Are services and supports for people with developmental disabilities resulting in outcomes which are aligned with the goals set through legislation?"

"Are the new support models resulting in improved outcomes for people?"

LEGISLATIVE GOALS

Colorado Revised Statutes (CRS 27-10.5-102-29) sets several expectations regarding the outcomes to be achieved through the delivery of services and supports to persons with developmental disabilities in Colorado. Specifically, this legislation defines services and supports as activities provided to "enable persons with developmental disabilities to:

- make increasingly responsible choices,
- exert greater control over their lives,
- experience presence and inclusion in their communities,
- develop their competencies and talents,
- maintain relationships, foster a sense of belonging, and
- experience personal security and self-respect."

PROGRAM EVALUATION

The Division for Developmental Disabilities (DDD) of the Colorado Department of Human Services (CDHS) mirrors the above legislative mandate in its mission statement and has developed a program evaluation process to evaluate service outcomes against the values embodied within legislation. Program evaluation is used to determine:

- if progress is being made,
- if new service models are more effective, and
- what improvements are needed.

The program evaluation methodology involves a longitudinal evaluation of service outcomes for a random sample of adults receiving services using the COPAR (Colorado Progress Assessment Review) instrument. Colorado interviews persons in services and persons providing these individuals with supports using the COPAR tool. The COPAR tool is designed to measure decision-making, community inclusion, talents, relationships, self-respect, security, productivity, and satisfaction.

OUTCOME ANALYSES

In analyzing the outcome information obtained through program evaluation, the Division makes four basic comparisons:

- comparison of outcomes across various service approaches to determine the relative effectiveness of these service approaches for achieving legislative goals,
- comparison of actual service performance against a performance target,

"Most of the innovations in approaches that have occurred over the past two decades have been generated at the state and local levels. These innovations include allowing people with disabilities to choose where and how they want to live and in what activities they want to participate, empowering families and consumers to take an active role in decisions affecting their lives, and emphasizing support for people in natural settings."

Wright and King, National Conference of State Legislatures, February, 1991

- comparison of outcomes longitudinally to see if there are system-wide improvements in outcomes across time, and

- comparison of outcomes by characteristics of persons in services, including differing demographic characteristics or support needs.

SERVICE APPROACHES

New support models are moving away from services which often focused on getting people "ready" before moving them into homes in the community or into integrated employment. Instead, the newer support models recognize that anyone can live in typical community settings, given the right supports.

New support models also recognize that when employment isn't an appropriate goal, then there can still be supports to meet friends and partake in integrated community activities rather than segregated "training" type services. Group homes in the community can still segregate people with developmental disabilities from the very neighborhoods in which they live. Therefore, newer support models emphasize smaller 1-3 person settings which provide more opportunities for meeting people and doing things in the community.

For the purpose of simplification, these newer support models are referred to as community individualized settings and are compared to the more traditional community group homes and institutional models within this report. By analyzing how outcomes vary across these major service approaches, we can determine if the new support models (providing individualized supports in smaller settings) are more successful than the older models of community group homes and institutional settings.

PERFORMANCE TARGETS

Since Wolfensberger (1972) coined the term "normalization", the concept has been widely embraced nationwide as a goal for services offered to persons with developmental disabilities. The "normalization" principle is that persons should be provided services which enable them to live lives which are as similar as possible to the patterns of everyday life for persons without disabilities. Therefore, the lives of adults in the Colorado general population can serve as a baseline against which the lives of adults with developmental disabilities may be compared. To develop that baseline, Colorado asked many of the same COPAR questions of a random sample of adults in the Colorado general population as were asked of adults receiving services.

PROGRESS OVER TIME

This report analyzes the COPAR information collected from a representative sample of 781 adults with developmental disabilities and a random sample of 1000 adults in the Colorado general population in two longitudinal studies conducted in 1992 and 1993. By asking the same people the same questions two years in a row, we can determine what changes are occurring for people receiving services.

"No person should be required to demonstrate a certain skill to graduate into an integrated setting. Living in an integrated world is not dependent upon possession of certain knowledge or the capability of performing a particular behavior."

Accreditation Council on Services for People with Disabilities, 1992

"It seems to us that analyses... of the habits and lifestyles of the general public can assist us in achieving social validity in our services to persons with developmental disabilities. It is easy to lose perspective on what might be considered quality of life without a yard stick that can provide a guide for programmatic and service decisions."

Kozleski and Sands, 1992

PROGRAM EVALUATION METHODOLOGY

ACCOUNTABILITY

Accountability is the cornerstone of all financial and programmatic reporting in government. "Accountability requires governments to answer to the citizenry to justify the raising of public resources and the purposes for which they are used." (Government Accounting Standards Board, 1987). In the absence of the profit measurement which is used by commercial organizations to establish accountability, governments must turn to outcome measurements which determine if they are achieving their legislatively mandated objectives.

HISTORY OF COPAR

To evaluate outcomes for persons receiving support against the values embodied within state legislation, Colorado has developed COPAR (Colorado Progress Assessment Review), a longitudinal evaluation program. This program was begun in 1986 in response to a legislative mandate that the State Auditor's Office (SAO) make an independent evaluation of the progress of individuals with developmental disabilities. From this mandate, a Steering Committee, made up of various stakeholders was formed to provide guidance to this evaluation. SAO recommended that this program evaluation process be continued and the legislature agreed and has provided DDD with funding to continue the COPAR longitudinal studies.

KEEPING THE PROCESS UPDATED

As legislative mandates and nationally recognized trends in service aims have progressed, the COPAR tool has been modified to enable it to stay abreast of these changes. For example, with the advent of the new legislative intent embodied in CRS 27-10.5 in 1992, additional outcome measures were added to COPAR, including measures related to competencies and talents, relationships, personal security, and self-respect. Additionally, information regarding rights restrictions and the use of psychotropic medications were added.

SPECIAL PURPOSE STUDIES

The COPAR survey process enables the Division to not only conduct outcome studies related to legislative intent of service, but also to collect different information of interest in any given year, such as use of psychotropic medications, criminal system involvement, need for custom wheelchairs, etc. Such information is used to support decision-making, special funding initiatives or provide planning information. Additionally, the COPAR is used in pre-post implementation of new program initiatives, such as CSLA (Community Supported Living Arrangements).

THREE-YEAR CYCLE OF LONGITUDINAL STUDIES

The longitudinal surveys are generally conducted in a three-year cycle. In the first year, information is collected on a new stratified random sample of adults with developmental disabilities who receive services funded by the Division. In the second year, the study is repeated asking questions of the same individuals, so that change can be accessed. The third year concentrates on analyzing the information and making changes to the form as necessary. Sample attrition occurs due to changes in who is receiving services, the service approaches used for those individuals, and/or movement between service areas. This necessitates drawing of new samples for each cycle of longitudinal studies.

1992 and 1993 COPAR SAMPLING PROCESS

This report will concentrate on the results of the most recent three year cycle, which includes COPAR surveys conducted in the summers of 1992 and 1993. A stratified random sample of 781 adults receiving services funded by the Division for Developmental Disabilities were surveyed in the summer of 1992. This sample was based on stratified random samples of 30 adults or 10% of the service population (whichever was greatest) which had been drawn from each Community Centered Board and Regional Center service population in 1992. The samples were found to be statistically representative of the populations from which they

"Among the actions legislators and program administrators can take to help ensure quality in their programs are the following:...establish a mechanism to monitor services, service outcomes, and consumer satisfaction..."

Wright and King, National Conference of State Legislatures, February, 1991

were drawn based on age, gender, ethnic status, adaptive skill level, residential setting, day program, and funding type. These same individuals were resurveyed in 1993. Due to sample attrition, 743 adults were surveyed in 1993. This represents an overall sample percentage of 13% (743/5562) for the active adult population. Attrition occurred for reasons including: death, refusal to be interviewed, and leaving the service area.

INTERVIEW PROCESS

Persons with developmental disabilities in the sample and persons providing them with services were interviewed "in person" using the COPAR tool. The satisfaction section can only be completed through interview with the person receiving services. However, other parts of the form are completed through interview with other persons providing supports. Generally speaking, at least 3 individuals must be interviewed to complete the COPAR form. The person in services, someone who provides supports in the home (parents or staff) and someone who provides supports at work or school (employer or staff). Standage Accureach, Inc., a private marketing research firm, conducts these interviews under contract to the Division.

CONTROLLING FOR RESPONSE BIAS

Research has demonstrated that individuals with mental retardation have two major tendencies, acquiescence and recency, when responding to questions (Rosen, Floor, & Zistein, 1974) (Sigelman, Budd, Spanhel, & Schoenrock, 1981) (Spanhel, Sigelman, Schoenrock, Winer, & Hromas, 1978). Acquiescence is the tendency to respond with a "yes" to questions. Recency is the tendency to select the last choice presented.

To ensure that persons were understanding the questions asked and that they were not being affected by the tendencies mentioned above, two sets of paired questions occur within the satisfaction section which ask the same information in two manners. One set reverses the order of two choices to test for recency. In the other set, a "yes" response is equivalent to a "no" response to test for acquiescence. All portions of the COPAR which relied on interviews with persons receiving services were discarded for any individual who did not provide consistent responses on these two sets of check questions. Other reasons for which individuals were not included in the analysis were inability or unwillingness of the person to be involved in the personal interview.

Of the 781 persons sampled from those receiving services, 350 (45.4%) of those adults were included in the satisfaction analysis in 1992 and 282 (38.0%) of the 743 adults surveyed in 1993.

Since a large proportion of the sample was discarded, it is important to determine changes in the characteristics of the satisfaction sample as compared to the total adult sample. The satisfaction sample has a smaller percentage of individuals at lower levels of functioning than does the sample as a whole. Since the average adaptive skills (overall functioning level) of persons served in institutional settings is lower than the average of persons in community settings, it is also not surprising to find that the satisfaction sample is composed of a higher proportion of individuals residing in community settings than is the total sample. Only 13 persons in institutional settings remained in the satisfaction sample.

Due to the changes in the characteristics of the satisfaction sample, the results of the satisfaction analyses should only be generalized to adults who require less support, except when the analyses specifically separate and present results by support levels.

GENERAL POPULATION STUDIES PROVIDE A PERFORMANCE TARGET

Since Wolfensberger (1972) coined the term "normalization", the concept has been widely embraced nationwide as a goal for services offered to persons with developmental disabilities. The "normalization" principle is that persons should be provided services and supports which enable them to live lives which are as similar as possible to the patterns of everyday life for persons without disabilities. This, then, sets a performance standard against which all services can be compared; that is, the everyday lives of persons without disabilities.

The lives of adults in the Colorado general population can serve as a baseline against which the lives of adults with developmental disabilities may be compared to see if the services being funded by this Division are affording similar opportunities to adults with developmental disabilities as are enjoyed by other adults within the state. Other investigators have recognized the importance of anchoring quality of life or service measures for persons with developmental disabilities to a baseline provided by the general public (Richardson, Katz, & Koller, 1993; Kozleski & Sands, 1992; Rosen & Burchard, 1990). Kozleski & Sands (1992) suggest that such information can "establish a yardstick by which outcomes of services to individuals with developmental disabilities could be measured" (Kozleski & Sands, 1992).

To develop this baseline in Colorado for service outcomes related to persons with developmental disabilities, the Division surveyed a random sample of 1000 adults in the Colorado general population in 1992 asking them many of the same questions as were asked of a random sample of 781 adults receiving services. The questions in common were related to life satisfaction, decision-

making, and activity levels. Additionally, adults in the Colorado general population were asked if they agreed or disagreed with many of the philosophies or values which guide our service system. This survey was repeated in 1993 asking questions related to relationships, self-esteem, personal security, and talents. The sample size was 692 in the second year, as only those persons who had agreed in 1992 to be resurveyed were contacted again in 1993.

The interviews were conducted by Standage Accureach, Inc., a marketing research firm under contract to the Division. They utilized a list of telephone numbers which were randomly generated within all of the Colorado extensions. This allowed all adults who have telephones to have an equal chance to be surveyed, regardless of whether they have their telephone number listed in a directory or not. Up to four calls were made to the same number to increase the likelihood of reaching someone at that number.

One of four age and gender categories was randomly assigned to these telephone numbers to control against a bias regarding who within a household answers the telephone. These categories were: youngest adult male, oldest adult male, youngest adult female and oldest adult female. The purpose of the study was explained to the person answering the telephone and the need to interview someone within the specified age and gender category was also explained.

"People first" language was used throughout the form. When talking to adults in the general population, the term "mental retardation" was used on the assumption that they would be unfamiliar with the term "developmental disabilities". However, it is believed that results can be generalized from persons with mental retardation to persons with developmental disabilities and so the latter term is used throughout the remainder of this report.

It is recognized that many of the differences observed may be due to differences in income, accessibility, and capabilities (particularly in terms of decision-making involvement). However, the general population can still serve as a baseline or performance target for services we provide to adults with developmental disabilities.

DEFINITIONS

The following terms are used throughout this report in figures and in discussions of analyses. To avoid possible misinterpretation, they are defined below:

Adults Receiving Services (also referred to as "All Services" on tables) refers to the random sample of individuals age 18 years and older whose services are funded through the Division for Developmental Disabilities (including all services and supports, whether receiving day, residential, community, or institutional services). Some of these individuals may be receiving residential supports and some are not. Some may reside with their parents, spouse, or other relatives while receiving a day service funded by the Division.

Note that when comparing the percentages listed under table columns with this heading, they will not always appear to be intuitively consistent with the percentages listed for the columns headed as Community Individualized Settings, Community Group Settings, or Institutional Settings (see definitions of these below). However, this is due to the fact that the "Adults in Service" column contains totals for persons receiving any type of service, whereas the other columns include just residential and supported living services and do not include adults who receive only a day service.

Adults in the General Population refers to the random sample of persons age 18 years and older who live in Colorado.

Community Individualized Settings (IRSS/SL) - provide individualized services and supports in small settings where persons live by themselves or with 1 to 2 other individuals. These may include supports provided within a family home. These include funding categories of Individualized Residential Services and Supports (IRSS) and Supported Living (SL). IRSS includes State-funded follow-along and apartments plus Medicaid Waiver funded Personal Care Alternatives (PCAs). Supported Living includes Title XIX funded Community Supported Living Arrangements (CSLA), which were very new at the start of these surveys and so are not well represented within the sample. Waiver Supported Living (WSL) did not exist during the survey period, but would otherwise have been included here.

Community Group Settings (GRSS) - provide services and supports in medium sized group settings of 4 to 8 persons, commonly referred to as group homes, and include the funding categories of Intensive ARS, Moderate Supervision, and Specialized group homes operated by Community Centered Boards (CCBs), private service agencies, and/or Regional Centers (RCs).

Institutional Settings - provide services within large congregate care facilities and include the funding categories of Intermediate Care Facilities for the Mentally Retarded (ICFs/MR) with 15 or more residents, RC campus facilities, and Nursing Homes.

Supported Living and Residential Services and Supports:

Follow-along - State-funded follow along provides training to adults who live in unsupervised independent living settings.

CSLA - Community Supported Living Arrangements are supports to enable adults with developmental disabilities to live in their own home or the home of their family.

State Apts. - State funded apartments provide supervision, training and other assistance in an apartment setting.

PCA - HCB-DD waiver funded Personal Care Alternatives provide personal and physical care, supervision as necessary and independent living training in a normalized environment of 3 or fewer persons.

Mod. GH. - HCB-DD waiver funded Intensive ARS and Moderate Supervision Group Homes provide training and 24 hour supervision to persons in a group home setting of 4 to 8 beds.

Spec. GH - HCB-DD waiver funded Specialized Group Homes provide training and 24 hour supervision in a group home setting of 4 to 8 beds to persons requiring more intensive services.

RC GH/Apts - Regional Center community 8 bed group homes operated by state institutions which provide training and 24 hour on-site supervision to persons requiring more intensive services. (These facilities were primarily funded by HCB-DD waiver in October, 1993, but were funded as ICFs/MR >15 at the time of the COPAR survey in 1992 and most of the 1993 survey.)

RC Campus - Regional Center campus is a state operated ICF/MR >15 institution providing training and 24 hour on-site supervision to persons requiring more intensive services.

ICF>15 - Medicaid funded Intermediate Care Facility for more than 15 persons which is privately operated and which provides 24 hour on-ste supervision and training.

NH - nursing home.

FSSP - Family Support Services Program - assistance to families to keep a family member with a developmental disability at home.

Home of Relative - parent, relative, or guardian home with no residential services or supports.

Statistical Significance Level - Statistical tests calculate the probability of mistakenly concluding that observed differences can be generalized from a sample to the population from which it was drawn, when no differences actually exist. "Significance level" is the term applied to this probability. Significance levels are commonly stated as fractions; for example, a level of .0001 would be interpreted as only 1 chance out of 10,000 that the sample results do not apply to the population. Obviously, it is desirable to minimize the probability of mistakenly concluding that there are differences. Therefore, results of statistical test are generally only considered to be statistically significant when at a level of 5 out of 100 (.05) or less. The smaller the fraction, the stronger the case for a difference.

NATIONAL RECOGNITION OF COLORADO'S COPAR PROGRAM EVALUATION PROCESS

COPAR has received national recognition as a process for evaluating outcomes of services to people with developmental disabilities. For instance, COPAR studies resulted in Colorado being one of four states highlighted in a monograph prepared for the 1994 National Conference of State Legislatures on "Promoting Quality in Developmental Disability Services".

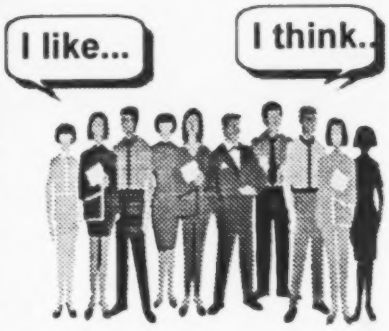
COPAR was also one of twelve model program evaluation programs which were nominated for presentation at a special conference on "Reinventing Quality" sponsored by the National Association of State Developmental Disabilities Program Directors in December, 1992. COPAR continues to be highlighted within the resource book on quality enhancement entitled *Reinventing Quality* which is published annually by the University of Minnesota and is available via electronic bulletin board and hard copy.

Forty-seven requests for information about the COPAR program evaluation process were received from across the nation during fiscal year 1993-94.

"Today, many adults around the country who previously were thought to require care in institutions or congregate group homes now live in typical housing and need less than full-time supervision. They participate in community life, with the assistance of individual supports that respond to their particular needs."

Wright and King, National Conference of State Legislatures, February, 1991

SATISFACTION WITH SERVICES



One of the goals of the Division for Developmental Disabilities is to ensure that persons in services are satisfied with the supports they receive, that they are given every opportunity to express their opinions, that support staff are trained to listen, and that every practical effort is made to align supports with those opinions. The Division for Developmental Disabilities recognizes that asking persons their opinion of services is one way of providing persons with an opportunity to exercise control over their lives.

National trends within industry in general and within the field of developmental disabilities support the concept that the opinion of your customer is a key measure of success. The Total Quality Management movement, the Self-Advocacy and Empowerment movements, and concepts behind Personal Futures Planning and Circles of Friends are just a few of these trends.

For our industry, the most important customers are persons with developmental disabilities. They are the reason our supports and services exist and they must ultimately define the parameters of the supports needed, how these supports should be offered, whether existing supports are successful, and what changes are needed to these supports.

There are several ways of determining customer satisfaction and of providing opportunities for customers' opinions to drive services. Discussions with and careful observation of our customers will give us a strong indication of their opinions and needs. Surveys, complaint files, self-advocacy groups, and focus groups are other sources for obtaining input. Involvement of persons with developmental disabilities on boards of directors, and other groups involved in the implementation and oversight of organization operations have also been used.

To take a state-wide look at the satisfaction of persons in services, the Division for Developmental Disabilities surveyed a random sample of over 300 persons with developmental disabilities in Colorado in 1992 and in 1993 to ask them how they felt about the services they were receiving and what changes they would like to see. This report addresses the following questions:

- Are persons satisfied with the services they receive?
- Does their satisfaction vary depending on the service approach?
- How does satisfaction with life compare for persons with developmental disabilities to other citizens of Colorado?
- Do satisfaction levels vary by age category, gender, or minority status?
- Are persons with developmental disabilities more satisfied with services in 1993 than they were in 1992?
- What would persons like to change about their homes and work or other day program activities?

Figure 1 provides satisfaction levels for adults receiving services by residential and supported living service approaches as compared to adults in the Colorado general population. In the first three columns of Figure 1, the satisfaction of adults receiving services is compared by service approach, with the statistical significance level noted in column 4 based on the Chi Square test.

In columns 5 and 6, the comparison is made between adults in services to that of other adults living in Colorado, with the statistical significance of differences noted in column 7 based on the Chi Square test. The last column provides the overall satisfaction level for adults receiving services in 1993, which can be compared to column 6 to see what changes have occurred from 1992 to 1993.

Figure 2 is very similar, except that the satisfaction questions relate to day services and are compared by integrated and non-integrated (segregated) day settings, plus a comparison to the general population.

While most general population information is from 1992, whenever the questions were new in 1993, the general population data is noted as such within that row.

Figure 1: Satisfaction of Adults with General Life Circumstances and With Home Related Supports

	Comparison of Service Approaches				Comparison to General Pop			Time
Questions Related to General Life Satisfaction and Satisfaction with Residential and Supported Living Services	**1993 Institutional Settings**	**1993 Community Group Settings (GRSS)**	**1993 Comm. Individualized Settings (IRSS/SL)**	**Significance Level**	**1992 Adults in General Pop.**	**1992 Adults In Service**	**Significance Level**	**1993 Adults In Service**
General Life Satisfaction	Col. 1	Col. 2	Col. 3	Col. 4	Col. 5	Col. 6	Col. 7	Col. 8
Are you usually happy or sad?				.02			.00001	
Happy	76.3%	82.6%	77.8%	instit. to	91.0%	68.5%		76.9%
In between		10.7%	16.7%	comm.	6.8%	27.3%		17.3%
Sad	23.7%	6.7%	5.5%		2.2%	4.2%		5.8%
Do you have enough friends? Are you lonely?				none			.00006	
Enough friends, not lonely	68.2%	73.6%	53.4%		78.5%	67.2%		60.2%
Maybe, sort of, not sure, don't know	17.6%	7.1%	11.9%		5.0%	5.8%		9.2%
Not enough friends, lonely	14.2%	19.3%	34.7%		16.5%	27.0%		30.1%
Are you satisfied with how you spend your spare time?				none			none	
Yes, like things done during free time	93.8%	89.0%	90.8%		82.8%	84.3%		92.0%
Maybe, sort of, not sure, don't know		5.7%	7.6%		5.5%	7.0%		5.8%
No, don't like things done during spare time, bored, not enough money or people to do things with	6.2%	5.3%	1.7%		11.7%	8.7%		2.2%
Do you have enough things to do around home during your spare time or do you get bored at home?				none	1993	NA	.00001	
Enough things to do	69.1%	58.5%	61.3%		90.3%			68.6%
In between, not sure, don't know	6.2%	7.2%	12.0%		2.7%			8.2%
Bored, not enough things to do	24.7%	34.3%	26.7%		7.1%			23.2%
Do people ask your opinion often enough when making decisions about you? Are you given enough choices?				none			.00001	
Yes	57.4%	64.3%	61.8%		95.3%	66.0%		64.8%
Maybe, sort of, not sure, don't know	30.4%	8.6%	12.0%			14.7%		10.0%
No	12.2%	27.1%	26.2%		4.7%	18.1%		25.2%
Satisfaction with Residential and/or Supported Living Services								
Do you like living where you live or not?				none			none	
Yes, like living here	84.0%	72.0%	85.5%		89.4%	85.8%		81.9%
Maybe, sort of, not sure		13.9%	7.8%		3.0%	5.1%		8.7%
No, do not like living here	16.0%	14.1%	6.7%		6.7%	9.1%		9.5%
Do you want to keep on living here?				none			.05	
Yes, want to keep living here	77.8%	71.3%	79.1%		72.8%	79.3%		80.1%
Maybe, sort of, not sure	6.4%	2.0%	5.8%		5.2%	3.9%		4.0%
No, want to move	15.9%	26.7%	15.1%		22.1%	16.8%		15.9%
Do you like the people who help you in your home? (who provide you with supports)				none	NA	NA	NA	
Yes	87.4%	87.4%	93.5%					91.8%
Maybe, sort of, not sure	12.6%	10.7%	4.5%					6.0%
No		1.9%	2.1%					2.2%
Is/Are the people who provide you with supports in your home polite and friendly to you?				none	1993	NA	1993 .007	
Yes,	84.0%	88.8%	95.2%		98.9%			92.3%
Maybe, sort of, not sure, don't know	6.4%	4.4%	4.0%		0.5%			4.9%
No	9.7%	6.8%	0.8%		0.5%			2.8%
Do you have enough privacy in your home?				none			.02	
Yes	95.5%	80.0%	93.9%		85.7%	81.7%		91.7%
Maybe, sort of, not sure, don't know		6.5%	2.1%		2.4%	5.8%		1.8%
No	4.5%	13.5%	4.0%		11.9%	12.5%		6.5%
Do people at home or work tell you what to do too often? Boss you around too much?				none	1993	NA	1993 .00001	
No, do not boss me around	81.1%	44.7%	59.7%		86.9%			62.9%
In between, not sure, don't know		8.8%	14.9%		3.0%			11.0%
Yes, people boss me around	18.9%	46.5%	25.4%		10.1%			26.1%
Sample Size	13	32	132		1000	350		282

Figure 2: Satisfaction of Adults with Day Services

	Comparison of Service Approaches			Comparison to General Pop			Time
Questions Related to Satisfaction with Day Services	**1993 Non-Integrated (Segregated) Day Services**	**1993 Integrated Day Services (CIE/SE & CP)**	**Significance Level**	**1992 Adults in General Pop.**	**1992 Adults in Service**	**Significance Level**	**1993 Adults in Service**
	Col. 1	Col. 2	Col. 3	Col. 4	Col. 5	Col. 6	Col. 7
Generally speaking, do you like your job(school)?			none			none	
Yes	88.0%	91.8%		89.3%	91.9%		90.5%
Maybe, sort of, not sure, don't know	9.2%	7.2%		3.9%	4.4%		7.9%
No	2.8%	1.0%		6.8%	3.7%		1.6%
Do you feel your job, day program or school is important to yourself or to others?			none	1993	NA	1993 .00001	
Yes	95.4%	89.6%		98.4%			91.4%
In between, not sure, don't know	1.9%	9.0%		0.2%			6.8%
No	2.8%	1.4%		1.4%			1.8%
Do you like the persons who provide supervision or support to you at work or school?			none			.0007	
Yes	96.2%	88.4%		90.2%	95.1%		91.1%
Maybe, sort of, not sure, don't know	3.8%	9.7%		3.9%	4.3%		7.7%
No		1.8%		5.9%	0.7%		1.2%
Do people at work, day program or school treat you with respect? Are they generally polite and friendly?			none	1993	NA	1993 .001	
Yes	88.5%	92.3%		97.2%			91.0%
In between, not sure, don't know	6.1%	6.1%		2.3%			6.1%
No, several people are not very nice	5.5%	1.6%		0.5%			2.9%
Do you feel the things you do at work, day program, or school are boring, do you need more challenge?			none	1993	NA	1993 .002	
No, rarely, never	55.4%	57.4%		63.9%			57.1%
In between, not sure, don't know	13.7%	20.4%		8.9%			17.9%
Yes, boring, often	30.8%	22.2%		27.3%			25.0%
Do you feel left out of things at work, day program or school?			none	1993	NA	1993 .00001	
No, never, rarely	62.2%	73.6%		76.9%			69.5%
In between, not sure, don't know	21.7%	12.3%		2.6%			16.2%
I feel left out sometimes, many times	16.1%	14.0%		20.5%			14.3%
Do you feel lonely at work, day program or school?			.003	1993	NA	1993 .00001	
No, not lonely, rarely, never	58.4%	76.7%		89.1%			70.8%
Not sure, in between, don't know	13.1%	11.8%		2.1%			12.4%
Yes, lonely	28.4%	11.6%		8.8%			16.8%
Sample Size	168	86		1000	350		254

OVERALL SATISFACTION FINDINGS - 1993 (Refer to Figures 1 and 2, last column, "1993 Adults in Service")

- **Most adults are satisfied with the residential and supported living services they are provided.** They like where they live (81.9%), the people who provide them with supports in their home (91.8%), they feel these people are polite and friendly (92.3%), and they have enough privacy (91.7%).
- **Regarding their jobs, day program and/or school, most adults like their day service** (90.5%), feel that what they do at their work, day program or school is important (91.4%), like the people who provide them with support there (91.1%), and they feel that people at their day program are polite and friendly to them (91.0%).
- However, it is of concern that:
  - Almost 1 out of every 3 adults receiving services state that they do not have enough friends and/or are lonely. About 1 out of 5 stated they were lonely at work.
  - Almost 1 out of every 4 adults are bored at home and do not have enough things to do around their home when they have spare time.
  - Approximately 1 out of every 4 adults indicated that people who provide supports in their home or work are too bossy and that they would like more involvement in making decisions.
  - About 1 out of every 4 adults feel their job or day program is boring and that they need more challenge.

COMPARISONS OF SATISFACTION IN RESIDENTIAL AND SUPPORTED LIVING SETTINGS - 1993 (Refer to Figure 1, Columns 1-4)

Three service approaches are compared in terms of the satisfaction of adults receiving these services. These three service approaches are: individualized settings (supported living or IRSS, column 3), community group homes (GRSS, column 2), and institutional settings (column 1). If the differences observed between these three service approaches are statistically significant, the significance level is noted in column 4 of Figure 1.

- For 10 of the 11 questions on Figure 1, there were no statistically significant differences in the satisfaction between community individualized settings, community group settings and institutional settings.
- Adults receiving residential services in institutional settings are more likely to describe themselves as being sad (15.2%) than are adults receiving residential services in the community (3.3%).

While the following differences were not statistically significant, they are still concerning and worth watching to see if they continue in future studies:

- 34.6% of persons in individualized community settings expressed loneliness, versus 14.2% and 19.3% in the other two settings.
- 46.5% of adults living in community group homes stated that people boss them around too much, as compared to 18.9 and 25.4% in the other two settings.
- A higher percentage of adults in community settings (61.8% to 64.3%) were satisfied with how often their opinion was asked when decisions were being made about them than in institutional settings (57.4%). However, 26.2% to 27.1% of the adults in community settings wanted more involvement as compared to only 12.2% of adults in institutional settings wanting more involvement.
- 14.1 and 16.0% of adults in community group homes and institutional settings said they did NOT like where they live, versus 6.7% in individualized settings. This is important to keep in mind when looking at the percentage of persons wanting to move. We all know from personal experience that you can like where you live and still want to move to an even better place.

  Since only 6.7% of the people living in individualized settings indicated that they did not like where they live, it would seem likely that the 15.1% wanting to move is comprised of people indicating a desire for an even better home.

Adults were also asked open-ended questions about what could be better about where they live or their life circumstances to allow them to clarify or elaborate on their responses to earlier questions regarding if they liked where they live.

For persons who were <u>dissatisfied with their community homes</u>, the areas of greatest concern were:

- 29.4% wanted their home to be cleaner or to have nicer furniture,
- 28.4% wanted to live in an apartment or another location (28.2%),
- 10.9% wanted a different roommate,
- 10.6% wanted to move nearer to family or friends, and
- 10.2% wanted more involvement in decisions.

For persons who were <u>dissatisfied with their home in an institution</u>, the areas of greatest concern were:

- 67.8% wanted to move to an apartment or another location,
- 32.8% wanted to move nearer to family or friends,
- 16.1% wanted to live with their parents or other family member,
- 16.1% expressed problems with other persons receiving services,
- 16.1% wanted their home to be cleaner or to have nicer furniture,
- 14.8% wanted better treatment by staff or a better relationship with staff, and
- 11.0% wanted more supports from staff.

COMPARISONS OF SATISFACTION WITH DAY SERVICES IN INTEGRATED AND SEGREGATED SETTINGS - 1993 (Refer to Figure 2, columns 1-3)

Two day service approaches are compared in terms of satisfaction of adults in services. These service approaches are: integrated day settings (Community Integrated Employment - CIE and Community Participation - CP) and non-integrated day settings (work activities, sheltered workshops, intensive habilitation, and other day services provided with a non-integrated setting) . If the differences observed between these two day service approaches are statistically significant, the significance level is noted in column 3.

- A high percentage of adults in all service approaches are satisfied with their day services regardless of whether the services were provided in an integrated or non-integrated setting
- For 6 of the 7 questions on Figure 2, there were no statistically significant differences in the satisfaction between non-integrated and integrated day program settings.

  This may be partially due to the fact that many people in integrated day services receive services within both integrated and segregated settings during different parts of the day or on different days. This also could be affected by rising expectations of persons in integrated settings.
- Adults served in integrated day programs (i.e. Community Integrated Employment or Community Participation) were less likely to be lonely (11.6%) than were adults receiving day programs in non-integrated settings (28.4%).

Adults were also asked open-ended questions about what could be better about where they work, go to day program or school in order to allow them to clarify or elaborate on their responses to earlier questions regarding if they liked their day services.

For persons who were dissatisfied with their integrated work or community participation day program, the areas of greatest concern were:

- 49.1% wanted a different job or job duties,
- 28.4% wanted to make more money at work,
- 11.5% wanted a better relationship with, or treatment by staff,
- 9.6% wanted more challenge at work,
- 9.6% wanted longer work hours, and
- 9.6% expressed problems with the physical environment at work (noise, or other environmental factors).

For persons who were dissatisfied with their non-integrated day program, the areas of greatest concern were:

- 52.0% wanted a different job or job duties,
- 25.5% had been unable to achieve a personal work goal at their current program,
- 18.6% expressed dislike of their work duties,
- 17.7% wanted more challenge at work or day program,
- 13.3% requested a change in the staff who support them at work or day program,
- 13.3% wanted different work or program hours,
- 13.0% wanted to make more money at work, and
- 12.2% wanted to have longer program hours.

GENERAL POPULATION COMPARISON - 1993 (Refer to Figure 1, columns 5-8; plus Figure 2, columns 4-7)

The satisfaction levels of adults in the Colorado general population can provide us with realistic goals for satisfaction levels. Please note that while most comparisons are made between the "1992 General Population" column and the "1992 Adults in Service" column, in some cases information was only available for 1993. In these cases, "1993" will be printed in the General Population column for the question affected and the comparison will be made to the "1993 Adults in Service" column instead.) When the differences noted between the Adults in Service and the General Population column are statistically significant, the significance level of that difference is noted in column 7 for Figure 1 and in column 6 for Figure 2.

Statistically significant trends include:

- Adults in the general population were more satisfied with their life circumstances than were adults in services in 11 of the 15 areas (Figure 1 and 2).
- A higher proportion of adults in the general population are usually happy (91.0%) than are adults receiving services (68.5%).

"Consumers represent an untapped source for information about what does and doesn't work in the design, delivery and assessment of services for the developmentally disabled."

Chuck Dougherty, The Quality Assurance Network, 1992

- A higher proportion of adults receiving services are lonely (27.0%) than are adults in general (16.5%). This is also true for loneliness at work; 16.8% of adults receiving services stated they were lonely at work, as compared to 8.8% of adults in the general population.
- A higher proportion of adults in the general population want to move (22.1%) than do adults receiving services (16.8%).
- A much smaller percentage of adults receiving services (66.0%) were satisfied with how often their opinion was sought when decisions were made about them than was true for other adults in Colorado (95.3%).
- More than twice as many adults in services (26.1%) feel they are bossed around too much as compared to adults in the general population (10.1%).

CHARACTERISTICS OF PERSONS RECEIVING SERVICES - 1993

- No statistically significant differences were found in satisfaction levels based on gender or minority status. However, it was noted that there is a general trend for satisfaction levels to go down with increased age (ANOVA, .0001) for both adults in the general population and for adults receiving services.

COMPARISON IN SATISFACTION FROM 1992 to 1993 (Refer to Figure 1, columns 6 and 8; and to Figure 2, columns 5 and 7)

- The percentage of individuals expressing satisfaction with the 18 areas surveyed in 1993 ranged from 60.2% to 92.3%. In 4 of the 9 satisfaction measures used in both years, the total percentage of individuals indicating satisfaction increased from 1992 to 1993. However, likewise there was a decrease in satisfaction on 4 of the 9 measures. On one measure the change was equivocal, since there was a change in those who were undecided, allowing the satisfaction to decrease at the same time the dissatisfaction decreased. These changes could not be tested for statistical significance.

Summary of Satisfaction Findings. While the majority of persons surveyed were satisfied with their services, many persons would like to see improvements. In general, satisfaction findings indicate a need for increased supports to make and keep friends, to use leisure time, and more involvement in decision-making.

"The best ideas for improving organizational processes come from the customers who depend on the organization's products and services.

The reason is simple: Quality in the modern sense is defined as meeting the needs of customers.

Who better than the customer can tell us what is needed and how we are doing?"

Berwick, Godfrey, and Roessner
Curing Health Care, 1991

DECISION-MAKING

One of the Division's legislatively mandated goals is that adults with developmental disabilities "make increasingly responsible choices" and "exert greater control over their life circumstances" (CRS 27-10.5-102-29). The ability to make choices and the choices you make is what distinguishes you from other people around you; it defines your individuality. The right to determine the direction your own life will take is also referred to as empowerment, self-direction, making choices, increasing independence, etc. But, regardless of what terms are used to describe it, the right to make decisions that affect your own life is a key attribute of adulthood. Decisions may range from the more mundane decisions about what to wear, what to eat, etc., to the more significant decisions about what job to pursue or home to select. Everyone wants to have control over their life circumstances. Adults with developmental disabilities are often not allowed this control, even in areas where health or safety are not concerns.

COPAR allows consumers (or other respondents answering for those consumers) to indicate the degree to which each consumer is involved in making decisions (or is provided independence) by asking if decisions were made independently, with the involvement of others or by others in each of several decision areas such as choosing their roommates, clothes to buy or wear, deciding how to spend spare time or spare money, etc. During a survey, consumers are always provided the opportunity to respond to these questions directly, but when they were unwilling or unable to, then other respondents familiar with the consumer's involvement in decision-making were interviewed. When consumers responded directly, a consistency check was performed to ensure that they were understanding the questions and not being affected by a desire to please or a tendency to select the choice offered most recently. (Refer to the methodology section of this report for further details.)

This section of the report compares the amount of involvement that adults with developmental disabilities have in making decisions about their own lives. This report will present information relevant to answering the following questions regarding involvement in decision-making:

- In what types of decisions are persons with developmental disabilities being involved and what level of involvement are they provided?
- Do opportunities for involvement in decision-making vary by service approach? If so, is this variation related to differences in the support needs of persons receiving those services?
- Are adults receiving services provided similar opportunities to make decisions as are other adults in Colorado?
- Does involvement in decision-making for adults vary by age, income, gender, or minority status?
- Are persons with developmental disabilities more involved in making decisions in 1993 than they were in 1992?

This evaluation has some limitations. No information is available to address issues such as how choices are presented; whether people are provided choices, but they are unable or unwilling to take advantage of these opportunities; or whether the decisions being made are "responsible" ones. This evaluation concentrates on the numbers and types of decisions in which people with developmental disabilities are involved and their level of involvement.

Figure 3 presents information relevant to answering these questions. The percentage of adults who are involved in different decision-making areas is compared by service approach in columns 1-3, with the statistical significance level noted in column 4 based on the Chi Square test. In columns 5 and 6, the comparison is made between adults in services to that of other adults living in Colorado, with the statistical significance of differences noted in column 7 based on the Chi Square test. The last column provides the total for adults receiving services in 1993, which can be compared to column 6 to see what changes have occurred from 1992 to 1993.

As you review this information, you can see how very limited decision-making is for many adults receiving services. As Figure 1 already identified under the satisfaction results, adults receiving services are less satisfied with their involvement in making decisions than are other adults in Colorado. As you look at Figure 3, it is easy to see why they are less satisfied.

Figure 3: Involvement in Decision-Making (note that this table is continued to the next page)

	Comparison of Service Approaches				Comparison to General Pop.			Time
Questions Related to Decision-Making	**1993 Institutional Settings**	**1993 Community Group Settings (GRSS)**	**1993 Comm. Individualized Settings (IRSS/SL)**	**Significance Level**	**1992 Adults in General Pop.**	**1992 Adults In Service**	**Significance Level**	**1993 Adults In Service**
Decision Areas Related To Supports In The Home	Col. 1	Col. 2	Col. 3	Col. 4	Col. 5	Col. 6	Col. 7	Col. 8
Who picked where you live? (if you do not live with relatives)				.00001			.00001	
I did	4.9%	2.7%	10.9%		42.1%	8.8%		10.0%
I did with someone else's help	14.3%	19.3%	63.1%		45.4%	34.1%		41.8%
Someone else did	80.9%	77.9%	26.3%		12.6%	57.1%		48.2%
Who picked who you live with, your housemates? or roommates (if you do not live alone & do not live with relatives)				.00001 IRSS to GRSS only			.00001	
I did	5.0%	1.0%	6.2%		75.4%	9.3%		5.1%
I did with someone else's help	23.3%	14.3%	38.7%		21.5%	21.9%		28.7%
Someone else did	71.8%	84.7%	55.1%		3.1%	68.7%		66.2%
If there are persons who regularly provide a paid service within your home, who hired or selected them? (if you have supports and if the supports are not being provided by relatives/parents)				.00001 IRSS to GRSS only			.00001	
I did	2.0%	1.8%	3.0%		56.2%	3.2%		2.5%
I did with someone else's help	13.6%	6.0%	27.7%		21.9%	15.1%		18.7%
Someone else did	84.4%	92.3%	69.3%		21.9%	81.7%		78.8%
Who chooses what you have to eat, drink and snack on at home?				.00001			.00001	
I do	8.3%	16.4%	48.4%		59.7%	15.8%		36.8%
I do with someone else's help	35.6%	50.6%	41.5%		24.4%	29.2%		40.2%
Someone else does	56.1%	33.0%	10.1%		16.0%	55.0%		23.0%
Who chooses decorations for your bedroom or home?				.00001			.00001	
I do	33.2%	30.2%	62.9%		57.5%	44.0%		50.6%
I do with someone else's help	27.9%	45.8%	29.4%		25.1%	31.0%		32.0%
Someone else does	38.8%	24.0%	7.8%		17.4%	25.0%		17.4%
Who chooses the clothes you own & wear?				.00001			.00001	
I do	33.3%	40.7%	62.7%		88.1%	64.1%		51.8%
I do with someone else's help	36.3%	40.1%	32.0%		8.2%	19.3%		35.0%
Someone else does	30.5%	19.1%	5.4%		3.7%	16.6%		13.2%
Who decides your daily and weekly schedule, such as when to eat, clean house or do laundry?				.00001	1993	NA	1993 .00001	
I do	8.8%	11.0%	43.8%		79.4%			31.9%
I do with someone else's help	26.7%	38.8%	43.0%		26.2%			35.3%
Someone else does	64.5%	50.2%	13.2%		4.1%			32.8%
Who decides how you spend your free time?				.00001			.00001	
I do	39.4%	44.7%	75.3%		73.9%	65.9%		64.9%
I do with someone else's help	34.6%	41.2%	21.1%		24.2%	24.1%		25.6%
Someone else does	26.0%	14.0%	3.6%		1.8%	10.0%		9.5%
Who decides what time you should go to bed/sleep?				.00001			.00001	
I do	45.2%	64.0%	86.7%		93.5%	67.0%		74.6%
I do with someone else's help	19.6%	23.1%	10.9%		5.5%	16.8%		14.8%
Someone else does	35.2%	13.0%	2.5%		1.0%	16.1%		10.6%
Do you have a key to your home or room and if so, who decides when you can use it?				.00001			.00001	
I have a key and use it as I wish	2.2%	7.9%	53.1%		95.7%	39.3%		35.0%
I have a key, but there are rules on when and how I use it	1.9%	1.0%	5.9%		3.7%	2.9%		5.1%
I do not have a key	95.9%	91.1%	41.0%		1.1%	57.7%		59.9%

Figure 3: Involvement in Decision-Making, continued

	Comparison of Service Approaches				Comparison to General Pop.			Time
Questions Related to Decision-Making	**1993 Institutional Settings**	**1993 Community Group Settings (GRSS)**	**1993 Comm. Individualized Settings (IRSS/SL)**	**Significance Level**	**1992 Adults in General Pop.**	**1992 Adults In Service**	**Significance Level**	**1993 Adults In Service**
Decision Areas Related to Home Supports, cont.	Col. 1	Col. 2	Col. 3	Col. 4	Col. 5	Col. 6	Col. 7	Col. 8
Who decides when you can get together with your friends?				.00001			.00001	
I do	41.5%	24.8%	60.5%		66.5%	45.0%		48.6%
I do with someone else's help	33.7%	55.6%	30.0%		29.4%	36.3%		36.0%
Someone else does	24.7%	19.6%	9.5%		4.1%	18.7%		15.4%
Who decides how to spend your personal money (spare $ not needed for necessities)?				.00001			.00001	
I do	15.5%	19.3%	51.9%		65.2%	39.0%		39.9%
I do with someone else's help	40.2%	49.5%	40.7%		31.7%	37.5%		39.9%
Someone else does	44.3%	31.2%	7.4%		3.0%	23.5%		20.2%
Can you decide whether or not to have pets in your home?				.00001			.00001	
I did	17.2%	27.2%	54.6%		33.2%	26.7%		39.9%
I did with someone else's help	24.7%	18.6%	7.0%		49.9%	25.6%		15.4%
Someone else did	58.2%	54.2%	38.4%		16.9%	47.8%		44.7%
Decision Areas Related To A Day Service								
Who picked your job, school or day program? (if you have one)				.00001			.00001	
I did	3.1%	2.2%	6.8%		94.4%	9.4%		6.3%
I did with someone else's help	21.9%	26.1%	54.8%		2.7%	34.7%		42.3%
Someone else did	75.0%	71.7%	38.4%		2.9%	55.9%		51.4%
Did you get to help pick the staff who help you at work or in your day program? Did anyone ask you about hiring them? Did you get to talk to several possible people and help pick one? (if you have staff help on a job or at a day program)				.005 IRSS to GRSS only	NA	NA	NA	
I did	0.0%	0.0%	2.3%					1.9%
I did with someone else's help	14.6%	6.8%	13.2%					10.7%
Someone else did	85.4%	93.2%	84.4%					87.6%
Who picked your doctor?	NA	NA	NA	NA			.00001	NA
I did					64.6%	9.6%		
I did with someone else's help					13.9%	8.9%		
Someone else did					21.5%	81.5%		
Who picked your dentist?	NA	NA	NA	NA			.00001	NA
I did					67.4%	8.6%		
I did with someone else's help					13.8%	7.8%		
Someone else did					18.8%	83.6%		
Questions About Training								
Does anyone give you help on how to make good choices, such as training in making choices or how to speak up for yourself?				none	NA	NA	NA	
Yes	58.4%	62.9%	57.9%					55.4%
Maybe, sort of, not sure	11.3%	9.5%	15.2%					11.9%
No	30.3%	27.6%	26.9%					32.7%
Do you want to get training or help in making choices or not?				none	NA	NA	NA	
Yes	30.4%	38.8%	34.2%					34.7%
Maybe, sort of, not sure		14.2%	15.9%					12.2%
No	69.6%	46.9%	49.8%					53.1%
Sample Size	68	142	232		1000	653		591

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OVERALL RESULTS - 1993 (Refer to Figure 3, last column)

- The majority of adults receiving services are independently making decisions about decorating their home (50.6%), choosing their clothes (51.8%), how to spend their free time (64.9%), what time to go to bed or sleep (74.6%).
- The majority of adults receiving services report that they receive training on making choices (55.4%) and approximately 1/3 of adults would like more training.
- The majority of adults receiving services have had no involvement in selecting: their roommates or housemates (66.2%); the people who support them in their homes (78.8%); their job or day program (51.4%); or the staff who support them in their job or day program (87.6%). Most adults receiving services also do not have a key to their home (59.9%).

COMPARISON OF DECISION-MAKING BY SERVICE APPROACH - 1993 (Refer to Figure 3, Columns 1-4)

Three service approaches are compared in terms of the involvement in decision-making of adults receiving these services. These three service approaches are: individualized settings (supported living or IRSS, column 3), community group homes (GRSS, column 2), and institutional settings (column 1). If the differences observed between these three service approaches are statistically significant, the significance level is noted in column 4 of Figure 3.

- **Individualized residential or supported living settings provided adults with more involvement in making decisions than did community group homes and/or institutional settings** in all 15 of the decision areas studied in 1993. (These differences were statistically significant for 13 of the 15 areas when compared to either community group or institutional settings and statistically significant for the other 2 areas when individualized settings were compared to community group settings.) **This supports Colorado's efforts to concentrate new resources and conversion of resources towards more individualized residential and supported living settings.**

  Some examples of the more dramatic differences are listed below:

  - 73.7% of adults living in individualized settings picked, or helped to pick, their home as compared to only 19.1% to 22.1% of those living in community group or institutional settings.
  - 44.9% of adults living in individualized settings selected, or helped to select, their roommates as compared to only 15.3% to 28.2% of those living in community group or institutional settings.
  - 89.9% of adults living in individualized settings are involved in selecting the food and snacks for their homes as compared to only 43.9% to 67.0% of those living in community group or institutional settings.
  - 86.8% of adults living in individualized settings have a say in their daily and weekly schedule as compared to only 35.5% to 49.8% of those living in community group or institutional settings.
  - 61.6% of adults living in individualized settings helped pick their job or day service as compared to only 25.0% to 28.3% of those living in community group or institutional settings.
- **Community group settings provided involvement in decision-making more frequently than did institutional settings** for 12 of the 15 areas studied in 1993, and these differences were statistically significant.

"Speaking for yourself begins in day-to-day life. To learn to act as a responsible adult, other people (parents, relatives, friends, and staff people) have to see you and treat you as a responsible adult every day."

Carabello and Bittinger - 20
Consumer Advocacy, 1992

Figure 4 compares the number of areas in which adults are involved in making decisions by the specific type of residential and/or supported living service they receive. (Refer to the Program Evaluation Methodology section earlier in this report for a definition of the service categories.) The purpose of this comparison is to determine if any of the individual service models are providing greater opportunities for making decisions and are, therefore, more in line with the legislative goal for increased decision-making. The significant findings portrayed in this chart are summarized below:

- All service approaches provide fewer opportunities for involvement in making decisions than are enjoyed by adults within the general population.
- Each of the various types of individualized settings (not just the average level across individualized settings as was discussed previously) is providing more opportunities than every type of community group and/or institutional settings.
- Adults on regional center campuses have fewer opportunities than adults in any other type of setting.

AREAS WHERE ADULTS ASK FOR MORE CHOICE

Adults who indicated they did not have enough choice were asked in what areas they would like more choice. Tied for the most frequent responses were a desire for more choice of jobs, choices at work and in leisure activities. Other responses included choices related to the home, food, friends, curfew, finances, clothing, bedtime, telephone usage, and "everything".

"We learn, when we respect the dignity of people, that they cannot be denied the right to participate fully in the solutions of their own problems...To give people help, while denying them a significant part of the action, contributes nothing to the development of the individual...Denial of the opportunity for participation is denial of human dignity and democracy. It will not work."

Saul Alinsky, 1992

Figure 4: Decision-Making Involvement by Type of Residential and Support Living Service - 1993

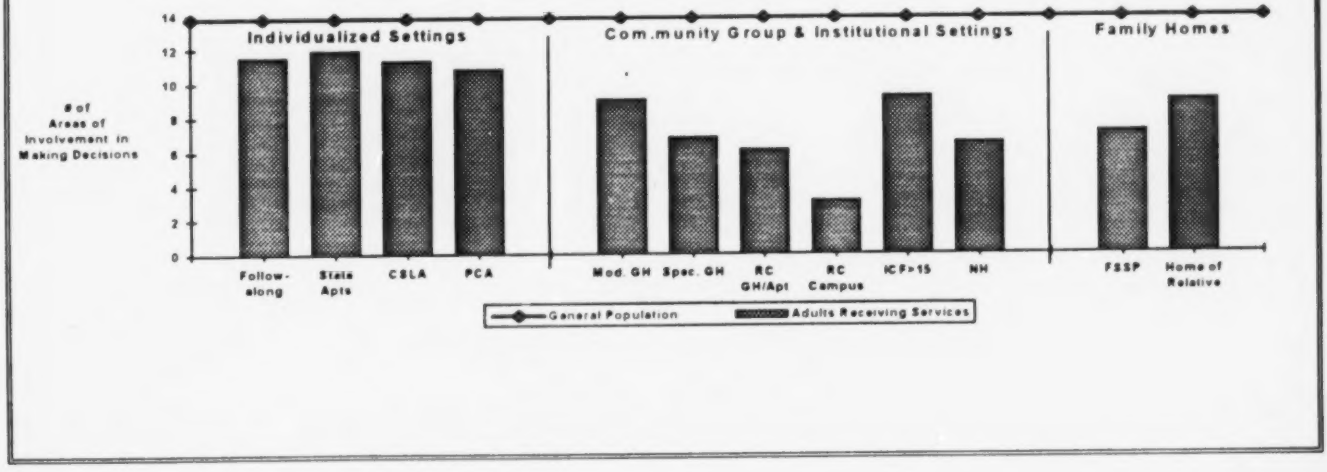
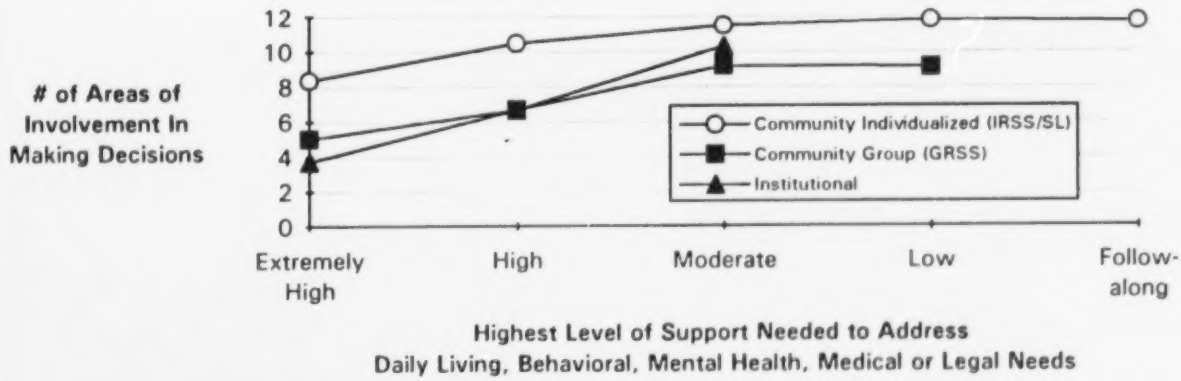


Figure 5: Decision-making Involvement by Support Level and Residential Setting - 1993



DIFFERENCES IN SUPPORT LEVEL NEEDS - 1993.

We investigated the potential that differences observed in decision-making involvement of adults by the major service approaches (i.e. individualized versus in community group or institutional settings) were more a function of the higher support needs of the adults in community group and institutional settings rather than a function of differences in service values or opportunities. This analysis involved a statistical comparison (ANOVA - Analysis of Variance) of the number of areas in which an adult is involved in making decisions by the levels of support they require to address their needs in the areas of daily living, behavioral, mental health, medical, and legal, using the highest support level provided across any of these need areas. However, as can be seen in Figure 5, adults were not served in community group settings if they only had follow-along support needs and, likewise, adults were not served in institutional settings if they had needed only low or follow-along supports.

The following trends were statistically significant (Figure 5):

- **Adults living in individualized community settings are provided involvement in making choices in more areas than are adults living in community group or institutional settings, regardless of their support level needs** (ANOVA, .001).
- **Adults are provided more involvement in choices as their need for support decreases regardless of service approach** (ANOVA, .001).

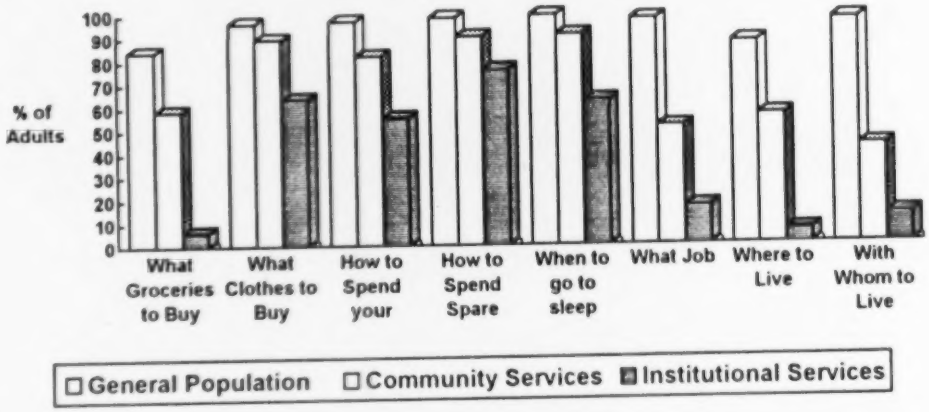
  This finding could support a conclusion that as persons are more capable of making decisions they are also being provided more opportunities to make decisions. This could be due to any number of factors, including an increased ability to communicate choices, increased assertiveness, or judgment by others that they are more able to make responsible decisions.
- Differences in the number of areas in which adults were involved in making decisions were very similar for adults living in community group and institutional settings.

WHAT STAFF OR OTHERS DO TO PROMOTE DECISION-MAKING

Staff, or others providing supports, were asked what they had done in the last month to promote opportunities for adults in services to make choices or to be more self-assertive. A higher percentage of staff who support adults in individualized settings provided examples than did staff supporting adults in community group homes or institutional settings.

The types of examples provided include: staff role-playing with the person in services, teaching better communication skills, training in decision-making skills, providing suggestions of choices, always asking what he/she wants to do or eat, wear, buy, or who he/she wants to live with or what kind of job he/she wants, explaining the negative and positive sides of issues, counseling for specific situations (e.g., confronting a roommate or sibling, looking for own apartment, finances, etc.), teaching rights and responsibilities, self-assertiveness counseling, how to make choices in stressful situations, peer counseling on making choices, giving fewer prompts over time, self-esteem

Figure 6: 1992 Comparison of Adults in Services to Adults in the General Population for Involvement in Making Decisions About ....



counseling, just not doing everything for him/her so choices will need to be made, reward system for making choices, developing a program to learn simple yes/no choices, and an eye contact program.

GENERAL POPULATION COMPARISON - 1992 (Refer to Figure 3, columns 5-8)

It might be argued that it is axiomatic that adults with developmental disabilities would make fewer decisions independently than other adults, due to the very characteristics which make them eligible for services. However, there is little reason that adults with developmental disabilities should not be involved in making decisions with the assistance of others. Therefore, the comparison to the Colorado general population is made in terms of involvement in making decisions (rather than independent decision-making). The involvement in decision-making afforded to adults in the Colorado general population can provide us with a benchmark for comparison to the decision-making opportunities provided to adults receiving services.

Please note that while most comparisons are made between the "1992 General Population" column and the "1992 Adults in Service" column, in one case information was only available for 1993. For that question ("who decides your daily and weekly schedule"), "1993" is printed in the General Population column and the comparison will be made to the "1993 Adults in Service" column instead.) When the differences noted between the Adults in Service and the General Population column are statistically significant, the significance level of that difference is noted in column 7 of Figure 3.

In all 16 decision areas surveyed for both groups, adults in the general population are more likely to be involved in making decisions than are adults receiving services. (These differences were all statistically significant.) However, to make this finding more meaningful, you need to look at each decision area and see how very large the discrepancy is. You also should think about what it would mean to you to not have the liberty to make such decisions or not even be involved. Can any of us imagine not being able to select the very food we eat every day, to have others pick out our clothes, or decorate our homes, or choose when, where, how and with whom we spend our spare time? Can we imagine having little or no say in where we live, our jobs, or the very people with whom we share our homes? Or even worse, can we imagine having little or no say in who will be providing us with intimate daily living supports, like helping us bathe ourselves, use the toilet, or dress?

Figure 6 presents a graphic comparison of the involvement in decision-making of adults receiving services (by type of service) to that of other adults in Colorado in just 8 of the 17 decision areas surveyed in 1992.

Some of the more notable differences in 1992 were:

- 57.1% of adults receiving services had NO involvement in picking where they live as opposed to 12.6% of adults within the general population.
- 68.7% of adults receiving services had NO involvement in selecting a roommate or housemate as opposed to 3.1% of adults within the general population.
- 57.7% of adults receiving services do NOT have a key to their home as opposed to 1.1% of adults within the general population.

- 55.9% of adults receiving services did NOT have any involvement in picking their job, school or day program as opposed to 2.9% of adults within the general population.

While a surprising number of adults in the general population also expressed no involvement in many of these areas (anywhere from 1% to 22%), this percentage was always substantially lower than for adults receiving services. Also, when the general population was asked if they would like to have more say in those areas, generally less than a fraction of one percent of them wanted more say. This indicates that they were allowing or asking others in their lives to make such decisions for them. This, then, was their decision.

DEMOGRAPHIC CHARACTERISTICS AND INVOLVEMENT IN DECISION-MAKING - 1992

Decision-making involvement was compared by age, income, gender, and minority status, with the following results:

- Income level did not impact the decision-making level of adults in the general population, but adults receiving services had more involvement in decision-making if they had an income than if they did not. Adults in the general population with the same income levels as adults receiving services still had higher involvement in making decisions.
- Adults become more involved in decision-making as they age from 18 to 35 years old, after which involvement levels out. This finding held true for adults in the general population and for adults receiving services. However, adults receiving services also showed a notable drop in involvement in decision making when they enter the 75 and older age range, which was not demonstrated for adults in the general population survey. This result is probably related to the fact that all of the adults surveyed within that age range lived in institutional settings.
- The involvement of adults in decision-making was slightly greater for females than for males. This difference was statistically significant only for adults in the general population.
- Minority status had no statistically significant impact on involvement in decision-making for adults in the general population.

  However, there was a tendency for adults receiving services to have slightly less involvement in decision-making if they were in a minority group, which held true both in community and institutional settings.

CHANGES IN DECISION-MAKING FROM 1992 TO 1993 (Refer to Figure 3, columns 6 and 8.)

- In 12 of the 13 decision areas measured in both years, the total percentage of adults who had no involvement decreased from 1992 to 1993. (Or, in other words, involvement increased in 12 of the 13 areas.) These changes could not be tested for statistical significance.
- This change is in keeping with our mission to provide more opportunities for adults receiving services to "exert greater control over their life circumstances" (CRS 27-10.5-102-29).
- This change is probably due to the increasing number of resources allocated towards individualized settings, as those settings have demonstrated much higher decision-making involvement than other settings.

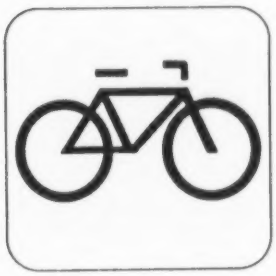
Summary of Findings Regarding Decision-Making. More opportunities for decision-making are being afforded by the newer community individualized settings than are available in community group homes or institutional settings. Therefore, these newer support models are more consistent with the mission to provide persons with opportunities to exert greater control over their life circumstances and to make increasingly responsible choices.

While there is evidence of system-wide increases in decision-making, there are still more improvements to be made, even in the individualized settings, as documented by comparison to decision-making levels of other adults within Colorado. *It is recognized that decision-making involvement may be limited, of necessity, due to the abilities of an adult receiving services. However, there is rarely a case in which no involvement is possible. It is clear from the analyses that many adults receiving services are not being provided as much involvement in decision-making as they are capable of having.*

"Personal life satisfaction increases when people are able to select their own goals, make choices, and exercise control over their life situations."

Accreditation Council on Services for People with Disabilities, March, 1992

COMMUNITY INCLUSION



There is a legislative mandate that services and supports to persons with developmental disabilities enable them to "experience presence and inclusion in their communities" (CRS 27-10.5-102-29). For the purpose of this evaluation, increased inclusion in community life is defined as participating in the everyday activities of life that are typical for most adults in our society.

People with developmental disabilities often find it more difficult to participate in everyday activities than do other people. Even when they are physically integrated in terms of living in an apartment or home within the community, they often are not provided the supports needed to assist them to take part in activities that the rest of us take for granted, like going to movies, grocery shopping, using local parks for recreation, joining clubs or special interest groups.

This report will present information relevant to answering the following questions:

- In what types of activities are people with developmental disabilities participating?
- Are some service approaches more successful than others in meeting the goals of community inclusion?
- Are adults with developmental disabilities provided similar opportunities for participating in their community as other adult citizens in Colorado?
- Is there variability in activity level by age, gender, minority status or support level?
- Are services providing more opportunities for community inclusion in 1993 than in 1992?

This evaluation is not intended to answer all questions regarding inclusion in community life. The evidence evaluated within this section will address only the numbers and types of activities in which persons with developmental disabilities are participating. No information is available to address whether they like these activities or whether they wish they could participate more often, less often or in different activities. The underlying assumption implicit in these analyses and in the conclusions drawn from these analyses is that participation in more activities is indicative of greater inclusion in community life which is a desirable outcome of services.

COPAR contains an activity checklist which asks whether adults receiving services have participated in each of several activities within the last two weeks (other time periods were used for the Political Activity area). This checklist provides a measure of community integration beyond simple physical integration in terms of location; it measures participation in activities which represent normal patterns of everyday life.

Figure 7 provides the percentage of adults who have participated in each of the activities surveyed. In the first three columns of Figure 7, activities of adults receiving services are compared by service approach, with the statistical significance level noted in column 4 based on the Chi Square test. In columns 5 and 6, the comparison is made between activities of adults in services to that of other adults living in Colorado in 1993, with the statistical significance of differences noted in column 7 based on the Chi Square test. The last column provides the activity level of adults receiving services in 1992, which can be compared to column 6 to see what changes have occurred from 1992 to 1993.

COMPARISONS OF COMMUNITY INCLUSION BY SERVICE APPROACH (Refer to Figure 7, Columns 1-4)

Three service approaches are compared in terms of the activity levels of adults receiving these services. These service approaches are: individualized settings (supported living or IRSS, column 3), community group homes (GRSS, column 2), and institutional settings (column 1). If the differences observed between these three service approaches are statistically significant, the significance level is noted in column 4 of Figure 7.

- **Adults receiving services in individualized settings are generally much more likely to participate in the activities listed than are adults who live in community group or institutional settings. This supports Colorado's efforts to concentrate new resources and conversion of resources towards more individualized residential and supported living settings.**
  - Adults receiving support in individualized settings participated more frequently in 28 of the 50 activities than did adults in the other two service approaches. These differences were statistically significant.
- On the average, adults in individualized settings were participating in 22 different activities as opposed to an average of 19 for adults in community group homes and 13 for adults in institutional settings.

Figure 7: Comparison of Activity Levels (note that this table is continued to the next page)

	Comparison of Service Approaches				Comparison to General Pop.			Time
Questions Related to Community Inclusion	1993 Institutional Settings	1993 Community Group Settings (GRSS)	1993 Comm. Individualized Settings (IRSS/SL)	Significance Level	1993 Adults in General Pop.	1993 Adults in Service	Significance Level	1992 Adults in Service
	Col. 1	Col. 2	Col. 3	Col. 4	Col. 5	Col. 6	Col. 7	Col. 8
HOUSEHOLD & PERSONAL BUSINESS								
Shopping for groceries	28.6%	50.9%	87.1%	.00001	93.3%	69.9%	.00001	60.5%
Shopping for other items	38.4%	66.5%	79.9%	.00001	75.4%	70.6%	.05	66.7%
Banking, paying bills	13.2%	38.1%	67.5%	.00001	85.7%	50.0%	.00001	41.3%
Obtaining services (such as hair cuts, dry cleaning, laundromat, home repairs, etc.)	31.7%	47.3%	52.5%	.006	46.2%	44.7%	none	36.3%
Visits to medical or dental services	32.1%	39.9%	41.8%	none	32.9%	34.6%	none	41.0%
ENTERTAINMENT/CULTURAL ACTIVITIES OUTSIDE THE HOME								
Dining out	46.2%	73.4%	85.0%	.00001	87.6%	76.7%	.00001	74.1%
Attending churches, religious services or events	35.9%	25.9%	40.9%	.005	40.9%	37.1%	none	35.1%
Attending clubs or organizations	6.7%	9.8%	18.1%	.007	27.0%	13.3%	.00001	15.0%
Visiting museums, libraries	22.6%	11.4%	15.9%	.none	28.6%	15.5%	.00001	17.7%
Going to movies, theaters,	24.3%	46.3%	37.8%	.005	29.2%	35.6%	.01	38.1%
Picnics, parks, zoos, etc.	50.4%	80.6%	53.6%	.00001	38.5%	57.1%	.00001	61.5%
Traveling away for vacations	6.6%	24.6%	25.3%	.002	29.2%	21.2%	.0009	23.0%
RECREATION FOR FUN OR EXERCISE								
Exercising at home	52.0%	52.5%	37.2%	.002	50.4%	41.7%	.002	45.8%
Walking, jogging, hiking	38.7%	71.5%	57.9%	.00001	68.6%	57.7%	.00006	70.8%
Participating in non-team sports	21.3%	34.3%	25.7%	none	35.5%	26.3%	.0004	36.6%
Participating in team sports	4.7%	13.4%	12.0%	none	13.6%	11.1%	none	14.9%
Attending sports events as a spectator	11.0	23.5%	17.5%	none	23.3%	18.1%	.02	18.9%
INTERACTION WITH PETS								
Pet care or recreation at home (if you have pets)	48.9%	69.0%	73.2%	none	93.7%	76.1%	.00001	60.7%
Pet care or recreation away (if you have pets)	0.0%	14.2%	24.1%	none	60.6%	24.3%	.00001	16.9%
POLITICAL ACTIVITIES								
Is registered to vote	10.0%	10.2%	23.5%	.0004	85.5%	19.6%	.00001	17.3%
Voted in the last year	6.2%	3.1%	12.8%	.002	81.1%	11.3%	.00001	6.8%

Figure 7: Comparison of Activity Levels, continued

	Comparison of Service Approaches				Comparison to General Pop.			Time
Questions Related to Community Inclusion	1993 Institutional Settings	1993 Community Group Settings (GRSS)	1993 Comm. Individualized Settings (IRSS/SL)	Significance Level	1993 Adults in General Pop.	1993 Adults In Service	Significance Level	1992 Adults In Service
	Col. 1	Col. 2	Col. 3	Col. 4	Col. 5	Col. 6	Col. 7	Col. 8
SOCIAL INTERACTION WITH FRIENDS								
Visits by friends to your home	16.5%	26.9%	56.8%	.00001	54.9%	36.4%	.00001	42.1%
Visiting friends at their home or elsewhere	17.5%	29.7%	60.0%	.00001	66.6%	41.6%	.00001	46.3%
Making calls to friends or others	6.8%	21.1%	47.2%	.00001	83.9%	34.3%	.00001	34.1%
Receiving calls from friends or others	19.3%	31.2%	51.1%	.00001	90.1%	42.4%	.00001	38.4%
Writing or dictating letters to friends or others	2.3%	3.6%	6.2%	none	15.9%	6.4%	.00001	5.4%
Receiving letters from friends or others	0.9%	5.2%	7.8%	.05 inst. to comm.	21.4%	7.4%	.00001	6.6%
OTHER SOCIAL ACTIVITIES								
Having parties or social affairs at your home	40.3%	35.9%	22.2%	.0004	13.5%	25.2%	.00001	26.3%
Attending parties or social affairs outside home	25.0%	56.5%	60.1%	.00001	52.3%	50.8%	none	45.9%
Interacting socially with others living in same home	75.3%	87.1%	86.9%	.03	83.6%	85.2%	none	81.5%
Going out on date with a girlfriend, boyfriend or spouse	4.6%	6.0%	18.2%	.00005	48.9%	12.4%	.00001	12.2%
SOCIAL INTERACTION WITH RELATIVES								
Visits by family or relatives to your home	33.9%	34.4%	33.0%	none	46.5%	42.5%	none	44.5%
Visiting them at their home or elsewhere	15.3%	31.0%	38.2%	.0007	56.7%	39.6%	.00001	40.2%
Making calls to family or relatives	18.8%	36.2%	51.1%	.00001	91.5%	43.1%	.00001	43.6%
Receiving calls from family or relatives	19.3%	31.2%	51.1%	.00001	90.1%	42.4%	.00001	43.1%
Writing or dictating letters to family or relatives	6.8%	6.1%	8.8%	none	27.6%	8.0%	.00001	6.8%
Receiving letters from family or relatives	8.9%	14.7%	14.4%	none	38.7%	14.1%	.00001	14.1%
ENTERTAINMENT AT HOME								
Playing cards, board games	37.4%	36.9%	34.8%	none	30.0%	35.8%	.03	35.6%
Participating in hobbies	41.5%	39.9%	46.2%	none	50.9%	43.4%	.007	49.2%
Using books, magazines	39.7%	53.7%	68.6%	.00001	92.0%	62.9%	.00001	76.0%
Listening to music on radio, phonograph, CD, etc.	91.3%	93.1%	94.4%	none	95.1%	92.0%	.03	89.7%
Watching television (cable TV, VCR tapes on TV)	84.5%	89.3%	95.0%	.004	98.4%	92.6%	.00001	93.3%
Napping	80.1%	77.9%	80.3%	none	70.7%	78.0%	.002	76.2%
Sitting around with nothing to do	90.7%	90.9%	85.7%	none	75.2%	84.1%	.00007	74.4%
HOUSEWORK & HOME MAINTENANCE								
Cooking, preparing meals	28.4%	67.4%	83.3%	.00001	93.5%	69.3%	.00001	63.1%
Doing dishes	25.0%	71.5%	80.1%	.00001	91.9%	71.7%	.00001	67.6%
Cleaning house	23.6%	78.7%	86.0%	.00001	89.2%	76.1%	.00001	75.1%
Laundry, ironing	26.7%	69.9%	76.8%	.00001	80.0%	63.6%	.00001	62.0%
Yard work, gardening	3.5%	21.8%	25.6%	.001	73.1%	26.6%	.00001	22.5%
Minor household maintenance	7.1%	12.8%	28.4%	.00001	74.6%	23.2%	.00001	22.7%
SAMPLE SIZE	59	160	263		566	692		779

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Figure 8: Activities by Type of Residential and Support Living Service - 1993

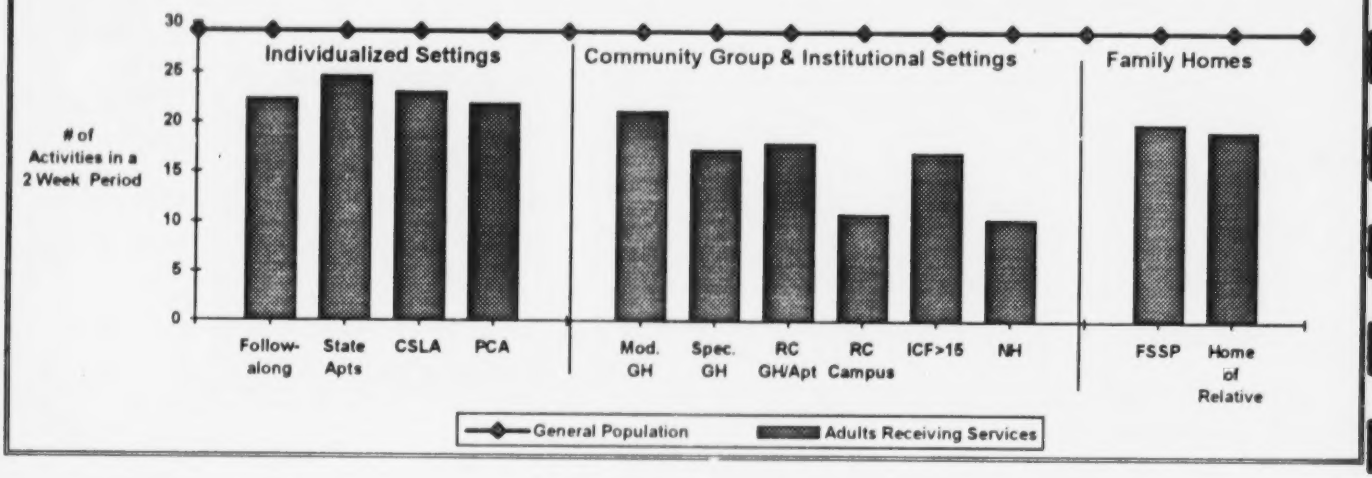


Figure 8 compares the number of activities in which adults with developmental disabilities participate by the specific type of residential or supported service they receive, if any. (Refer to the Program Evaluation Methodology section earlier in this report for a definition of the service categories.) The purpose of this comparison is to determine which service types are the most successful in providing community inclusion and which are, therefore, most in line with the legislative mandate for community inclusion. The activity level of the Colorado general population is provided for comparison purposes.

The following statements summarize this figure:

- All types of individualized settings provide more opportunities for participating in activities than do other residential settings. However, Moderate group homes are providing activity levels similar to that of Personal Care Alternatives (PCAs).
- Of all group settings, moderate group homes are doing the best job of providing community inclusion.
- The settings providing the fewest opportunities for community inclusion are Regional Center campuses and nursing homes.
- None of the current residential or supported living services offered to adults with developmental disabilities are resulting in activity levels similar to that of other adults in Colorado. Thereefore, there are improvements to be made in all residential and supported living services.

ARE ACTIVITIES DONE WITH OTHERS FROM THE SAME HOME?

One concern is that adults with developmental disabilities often participate in the community in groups. The concern surrounds the belief that other people in the community are less likely to interact freely with a group of people with disabilities than they would on a one-to-one basis. Therefore, for 18 of the activities on Figure 1, the survey asked if they were done alone, with others from the same home, with others from outside the home, or some combination. Adults provided individualized

"But when you have a disability... you are literally removed from others and placed in completely separate classrooms and told that when you learn those skills then you can belong. Of course we have a perfect Catch-22. People can't belong until they learn the skills, but they can't learn the skills because we never allow them to belong."

Kunc, A Need for Belonging, TASH Newsletter, 1992

services were less likely to be participating with a group of persons who live in the same home for 12 of the 18 activities studied. Other adults in Colorado were less likely to participate with others from their own home in 15 of these 18 activities than were adults in services. The only activities which adults in the general population were more likely to do with others from their home, than adults in services, were: attend parties, attend church and travel for vacations.

SUPPORT LEVELS - 1993

A special analysis investigated the potential that the differences observed in activity levels of adults in different service approaches were more a function of the higher needs of the adults in group or institutional settings than a function of differences in service values or opportunities. This involved comparison of activity levels of adults based on the highest support level provided to address their needs in the areas of daily living, behavioral, mental health, medical, and legal. A total activity score was calculated by counting the number of activities in which each individual was involved with an adjustment for missing data.

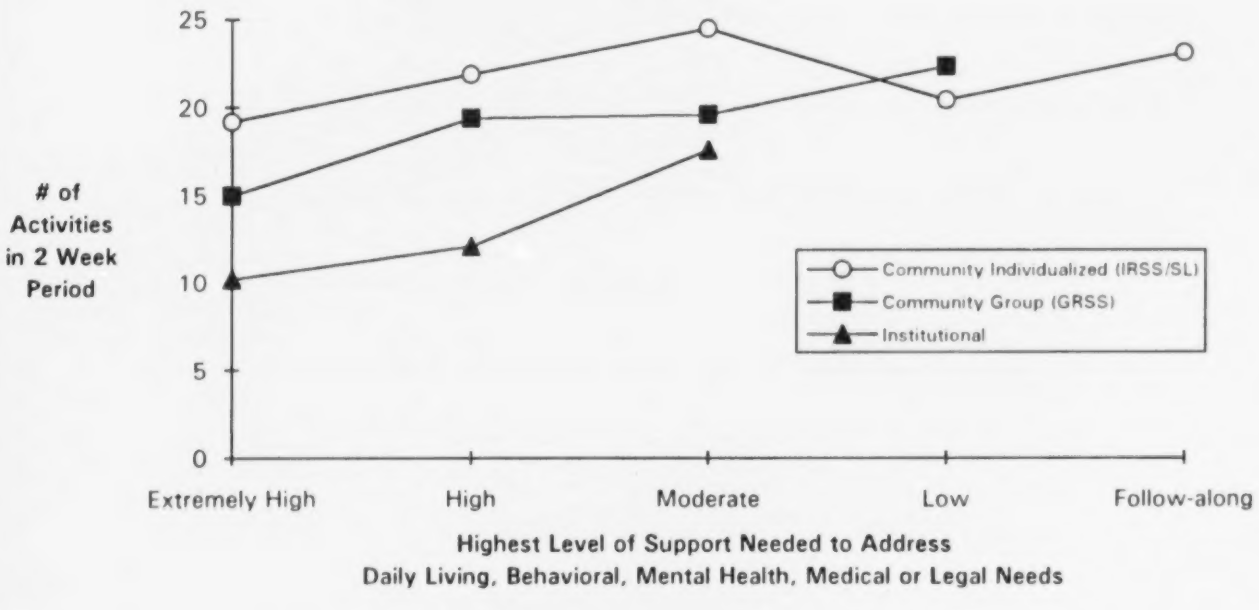
Adults are not served in community group settings if they only have follow-along support needs and, likewise, adults are not served in institutional settings if they need only low or follow-along supports. Therefore, comparisons of activity levels across service approaches cannot be made for support levels not held in common across all levels.

It can be noted from Figure 9 that:

- For support levels in common across all three service approaches (i.e., extremely high, high and moderate), adults receiving individualized settings had more community inclusion than did adults with comparable support levels who resided in community group homes or institutional settings. (ANOVA, .001) At the low support level, community individualized and community group settings provided a similar level of community inclusion.
- Insufficient information is available to comment on the anomaly that adults receiving a low support level had more activities if they were in a community group home than if they were in an individualized setting. However, the difference was not statistically significant.

Therefore, it may be concluded that differences observed in community inclusion for adults by service approach are indeed due to differences in the services themselves and not due to differences in the support level needs of the adults who receive those services.

Figure 9: Activities by Support Level and Residential Setting - 1993



GENERAL POPULATION COMPARISON - 1993 (Refer to Figure 7, columns 5-7)

The activity levels of adults in the Colorado general population can provide us with performance goals for community inclusion for adults with developmental disabilities. The following findings are based on a comparison of columns 5 and 7 of Figure 7. When the differences noted between the Adults in Service and the General Population column are statistically significant, the significance level of that difference is noted in column 7.

- **Adults in the general population participate more frequently in 38 of the 50 activity areas surveyed than do adults receiving services and these differences were statistically significant**.
  - **Activities Overall.** On the average, adults in the general population were participating in 29 activities in any given two week period as compared to an average of 20 activities for adults receiving services (t-test, .001).
  - **Activities in the Community** - Adults in the Colorado general population are more likely to do things in the community including shopping, banking, dining out, attending clubs, participating in non-team sports, taking pets for walks, and voting than are adults receiving services.
  - **Social Activities** - Most adults in the general population are more likely to have social activities, including visiting with friends and relatives, calling or receiving calls from friends and relatives, corresponding with friends and relatives, and going on dates than are adults receiving services. For example, adults in the general population are twice as likely as adults receiving services to receive calls from or to make calls to friends.
  - **Activities in the Home** - Regarding activities related to the home, the general population is more likely to participate in hobbies, use books or magazines, listen to music, do housework and house maintenance activities than are adults receiving services.
- **Adults receiving services participate in the following 5 activities more than other adults in Colorado: going to movies, picnics/parks, playing games/cards, napping and sitting around doing nothing**. These differences were statistically significant.
- Seven activity areas showed no significant differences.
- **Some of the more notable differences in the social lives of adults with developmental disabilities** as compared to the lives of other adults in Colorado include:
  - Half of adults in the general population had friends over during a 2-week period as compared to one third of adults in services.
  - 4 out of 5 adults in the general population made calls to friends over a 2-week period as compared to about one third of adults in services.
  - About half of adults in the general population went on a date during a 2-week period as compared to about one out of ten adults in services.
- **General Population vs. Adults Receiving Services in Group or Institutional Settings** - The activity level of adults in community group and/or institutional settings is even more drastically curtailed in comparison to the general population than for adults receiving services overall or in community individualized settings. (Compare columns 1-3 and 5 of Figure 7.)

DEMOGRAPHIC FACTORS - 1992

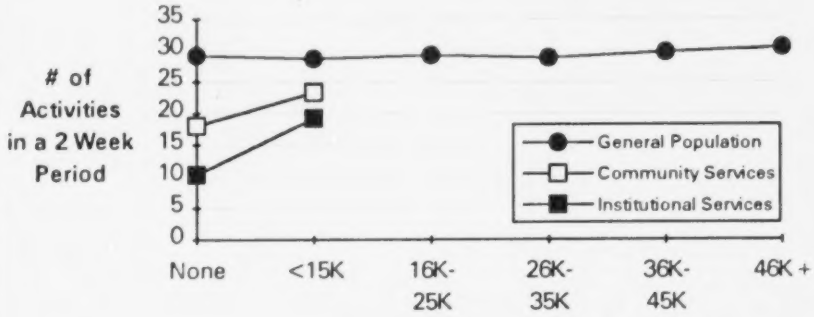
Income

The potential impact of income on activity levels was examined using a two-way ANOVA (Analysis of Variance), which is a statistical approach for examining the relative impact and interaction of two variables on a third variable. In this case, we examined the impact of income and disability on the total number of activities participated in during a two-week period (Figure 10). For adults with developmental disabilities, we also examined the impact of whether they received residential services in the community or in an institution.

Income level was found to have no impact on the number of activities undertaken by adults in the general population. Adults receiving services were found to participate in more activities if they had some income than if they had none. Adults receiving services fell into only two income categories: no earned income and income under $15,000.

When adults receiving services were compared to adults in the general population at the very same two income categories, it was found that adults receiving services still participated in significantly fewer activities than did adults in the general population at the same income levels.

Figure 10: Activities by Income & Population Category



Therefore, income is not the basis of the differences in activity levels. These differences were found to be statistically significant (ANOVA, .001 for main effects, .001 for interaction effects for general population compared to adults receiving services and .007 for adults receiving residential services in the community to those receiving residential services in institutional settings).

Age

The potential impact of age on activity level was examined (Figure 11). A general trend was observed in which adults are participating in fewer activities as they age. This trend was most noticeable for adults living in institutional settings. (No explanation is offered for the anomaly observed: where adults living in institutions moving from the 21-24 age category to the 25-34 age category show a notable increase in activities.)

Another trend, which is quite noticeable, is that regardless of age group, most adults living in Colorado are more active than adults with developmental disabilities and this difference is even more dramatic when the comparison is to adults living in institutional settings (ANOVA, main effects were .001, interaction effect was .001 for general population compared to adults receiving services and .012 for adults receiving community residential services to those receiving institutional services.).

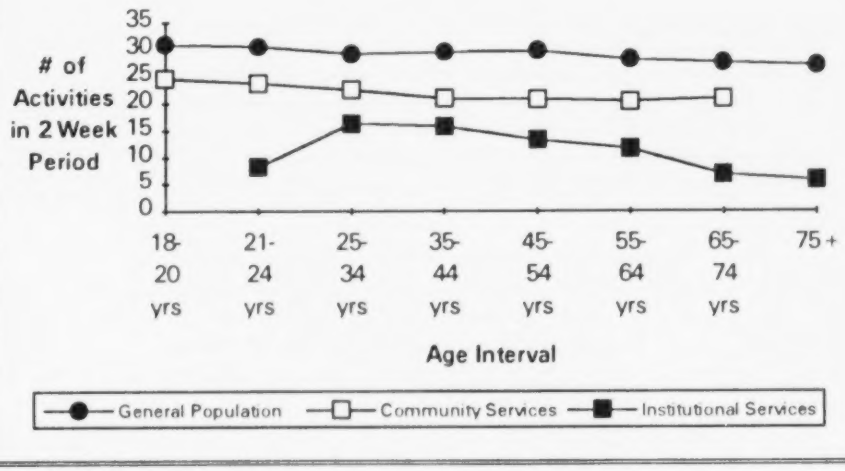
Gender

Female adults have a slightly higher activity level than do male adults (an average of one additional activity (ANOVA, .015). This difference was primarily due to the general population and was not found when the comparison was made just for adults receiving services.

Minorities

There were no statistically significant differences in the activity levels of adults in the general population or adults receiving services in terms of their ethnicity.

Figure 11: Activities by Age & Population Category



CHANGES IN COMMUNITY INCLUSION FROM 1992 TO 1993

There was an increase from 1992 to 1993 in the percentage of adults participating in 28 of the 50 activity areas studied. However, there was a decrease in 21 of the 50 areas. These changes could not be tested for statistical significance. To improve these outcomes, there is a need to concentrate our efforts on service approaches which were shown to provide the greatest opportunities for community inclusion, i.e. individualized settings.

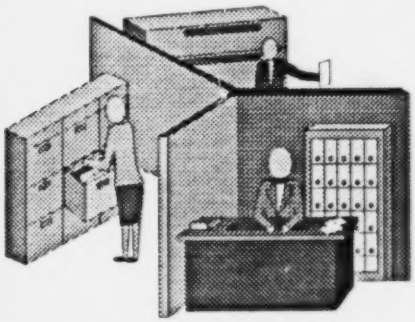
Summary of Community Inclusion Findings. Adults served in individualized settings are much more likely to participate in activities typical of other adults in Colorado than are individuals served in community group homes or institutional settings. Therefore, individualized services are more in line with the mission to increase opportunities for persons with developmental disabilities to be included in Colorado community life.

There was evidence of only very modest progress from 1992 to 1993 towards the goal of including persons with developmental disabilities in more community activities, when the entire service system was considered. The service system should continue to strive to provide more opportunities for persons with developmental disabilities to participate in the activities to which most citizens of Colorado have access.

"I'd like to see more things going on than now. All we do is sit around when there's nothing to do. I am stuck home too much. Too much TV. I want a hobby and to do more walking."

Direct quote from an adult receiving services, COPAR survey, excerpted from Ruth and Struxness, Fall, 1992 Director's Report.

COMMUNITY INTEGRATED EMPLOYMENT



People with developmental disabilities often have very low incomes. Additionally, services have historically segregated persons with developmental disabilities from other persons. Community integration is important not just in terms of where you live, but also where you work, go to school and spend your spare time.

Wright and King, National Conference of State Legislatures Task Force, 1991, state that: "Assumptions about what constitutes good vocational programming are changing. Individuals with severe disabilities previously were thought to require training in segregated sheltered workshops or adult training centers before entering the work force. Historically, most people entering these training facilities never left. Today, professional are moving toward newer models, such as supported employment, where job coaches help individuals who work in paid jobs, often side by side with workers without disabilities."

Colorado is committed to providing support and opportunities for adults with developmental disabilities to have paying and satisfying jobs in the community. When work is not an appropriate goal, then community participation is the preferred day service.

The goal of the Division's Community Integrated Employment (CIE) program is to obtain competitive employment for individuals with developmental disabilities in integrated community work settings while gradually reducing the amount of specialized on-site training or on-going support services.

GROWTH IN THE CIE PROGRAM FROM 1985 to 1993

The Division initiated supported employment in FY 1985. That project provided supported employment to 122 adults in 13 of the 20 Community Centered Board service areas in FY 1985. By the end of FY 1988, the program was expanded to encompass the service areas of all CCBs and 876 individuals were being served.

As Figure 12 shows, **there has been rapid growth in the percentage of adults served by the Division who are in CIE.** Not only has enrollment increased from 122 adults in 1985 to 2092 adults in 1993, but the number of adults who are enrolled in CIE for whom jobs have been found has also increased from 117 to 1484 adults. Additionally, while about 1 out of 5 adults receiving a day program in 1987 were receiving CIE, now almost half of adults in day program are in the CIE program.

Figure 12: Community Integrated Employment: Enrollment and Employment From 1986 to 1993

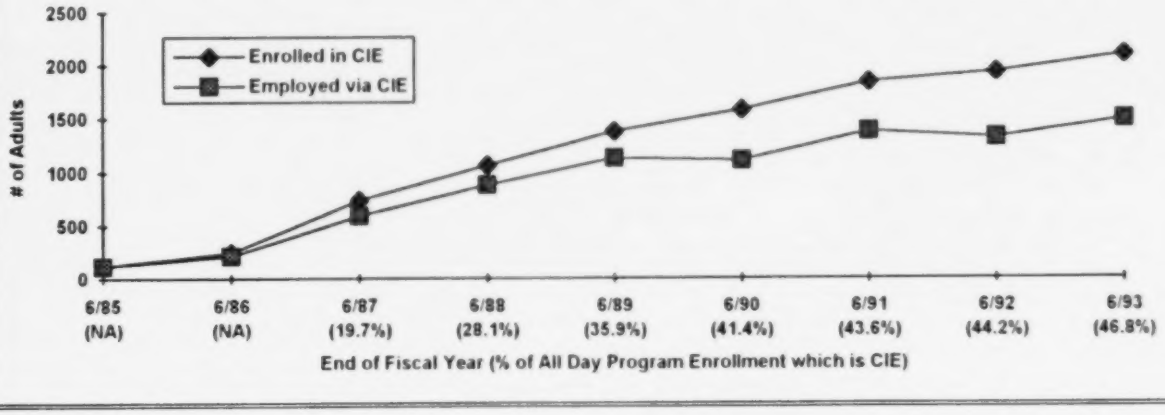
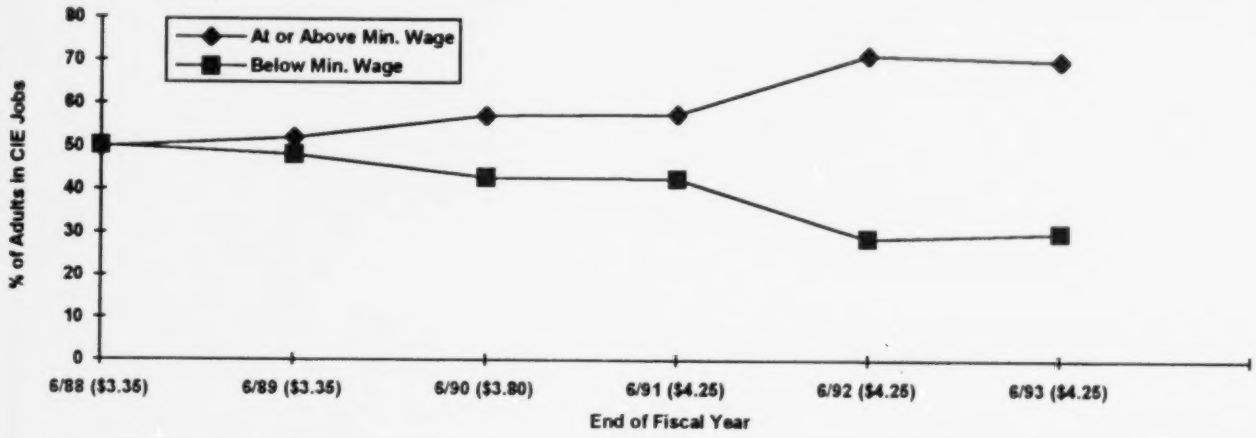


Figure 13: Comparison Of Wages Earned In An Average Week By Individuals In The CIE Program From 1986 to 1993



COMPARISON OF CIE WAGES TO MINIMUM WAGE FROM 1985 TO 1993

It is a goal that adults with developmental disabilities earn minimum wage or better. The following points summarize findings regarding this goal (Figure 13):

- The percentage of adults earning at or above minimum wage increased from 1988 to 1992 and then held steady from 1992 to 1993.
- Approximately 70% of adults receiving CIE services were earning at or above minimum wage in 1993.

GROWTH IN AVERAGE WEEKLY HOURS OF EMPLOYMENT FROM 1988 TO 1993

It is also a goal that adults work at least half-time or better (i.e. 20 hours/week or more). Figure 14 below shows the growth in the percentage of individuals holding community integrated jobs as a function of the number of hours they worked in an average week. Except for 1989, most adults with CIE jobs were working at least half-time. The percentage of adults with CIE jobs who are working 20-40 hours per week has increased since 1985.

Figure 14: Percentage of Adults in CIE by Average Number of Hours of Work in Community Jobs From 1986 to 1993

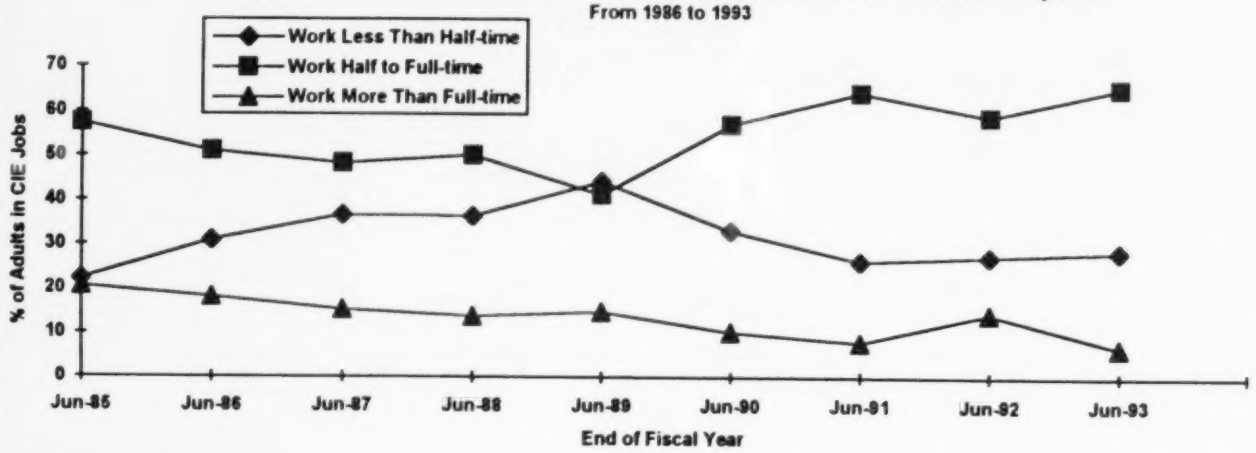
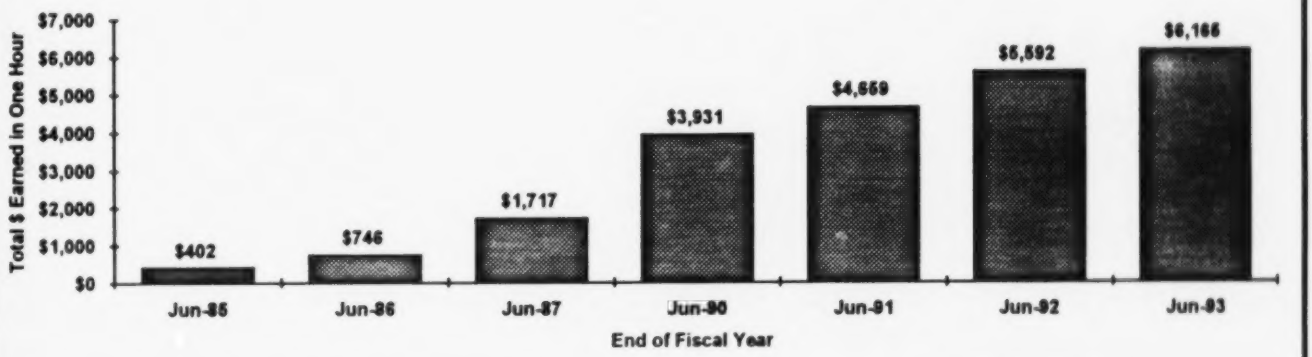


FIGURE 15: Total Projected Earnings in One Hour by All Individuals Employed in CIE From 1985 to 1993

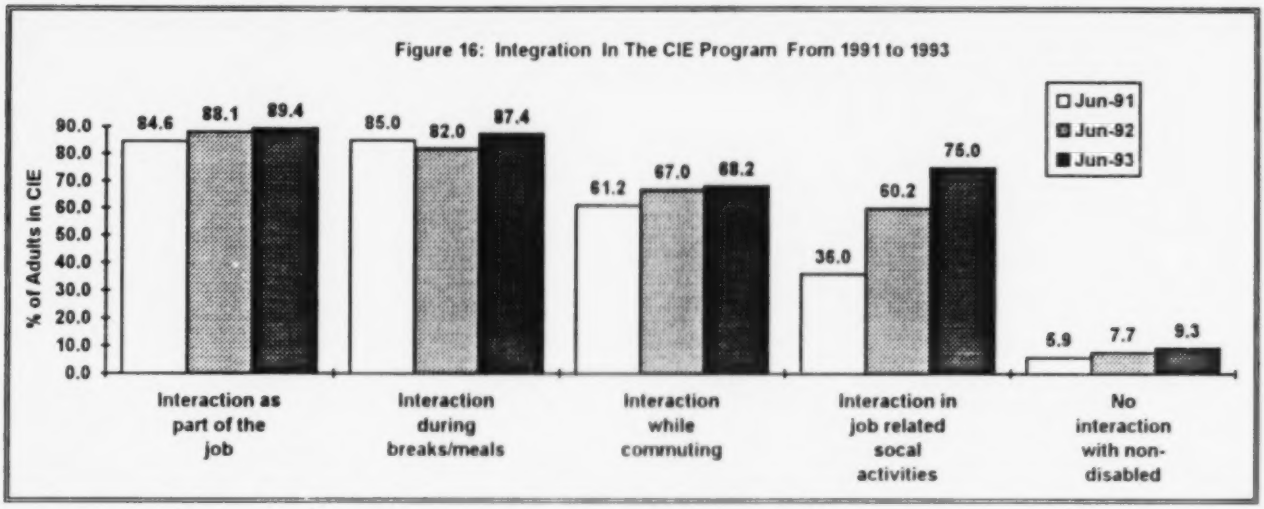


GROWTH IN TOTAL EARNINGS FROM 1985 to 1993

Through their earnings, adults with developmental disabilities provide both a benefit to themselves and to the Colorado economy. Benefits include increased buying power and tax contributions. Figure 15 shows the sum of the average hourly wage across all adults having community supported jobs. Overall, the total dollars earned in an average hour by the total of all adults employed through CIE has increased from $402 in 1985 to $6,165 in 1993.

"By working together, legislators, state agency personnel, and business leaders can create a climate in which people with developmental disabilities will have an opportunity to work and receive fair wages and benefits."

Wright and King, National Conference of State Legislatures, February, 1991



CHANGES IN COMMUNITY INTEGRATION

Having a job is just one aspect of community integrated employment. Another goal of CIE is for the jobs to be integrated in the community, and not just in terms of physical presence, but also in terms of interactions with other people at the work site and in the community.

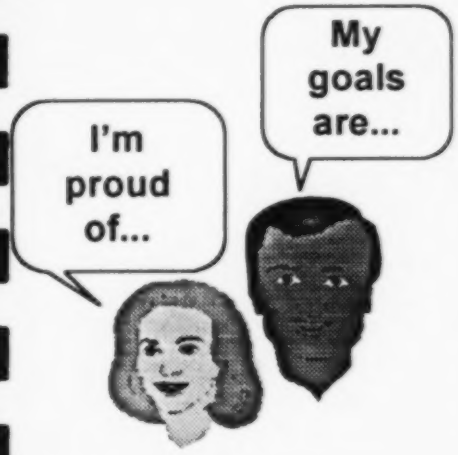
Figure 16 provides information pertinent to evaluating if community inclusion is occurring through CIE jobs. Nearly 9 out of every 10 adults in CIE are having interactions with others as a part of their job and during breaks and meals. 7 out of 10 are interacting with others while commuting to and from work, and during social activities related to their job. In all cases, these interactions have increased from 1991 to 1993. However, nearly 1 out of every 10 adults in CIE do not have interactions as a part of their jobs. It is likely that these are jobs, such as janitorial or other work crews, which either work at hours when other people are not present at the work site or which do not have opportunities for interaction, such as landscaping. These types of community jobs are still valued work; however, they do not provide opportunities to form social relationships.

Summary of Community Integrated Employment Findings: Steady and dramatic increases have been made in finding community jobs for adults with developmental disabilities. There are still improvements to be made in finding jobs for those seeking them and in finding jobs which provide opportunities for social interactions.

"I work with children of all ages from infants to preschool. Everyone who works with me is very nice and helpful. I keep very busy ... Through the CIE program I really managed to climb up the ladder. I've had to learn to make decisions."

A direct quote from an adult receiving CIE services during a COPAR survey, excerpted from Ruth and Struxness, Fall, 1992 Director's Report.

TALENTS AND PERSONAL GOALS



There is a legislative mandate to provide services which assist persons with developmental disabilities to "develop their competencies and talents" (CRS 27-10.5-102-29). COPAR surveys have historically looked at the skills of persons in services in terms of their abilities to perform self-care tasks (eating, bathing, dressing, etc.) and other independent living skills (making purchases, reading, math skills, ability to get around the community unassisted, etc.) (Refer to the *Report On A Three Year Longitudinal Study Of Consumer Outcomes, 1989* for information regarding the results of surveys of basic self-help and independent living skills.) However, a COPAR Advisory Committee decided that the 1993 COPAR survey should be expanded beyond the narrow definition of talents in terms of basic self-help or independent living skills. The Committee followed the guidelines of the Accreditation Council on Services for People with Disabilities (1992), which stated that "personal goals provide most people with motivation and direction. The service process should seek to understand individual goals and to support activities that will contribute to individual achievement of personal goals....Education and training should be based on personal goals." Therefore, the 1993 COPAR survey concentrated on answering the following two questions:

- are people in services proud of anything they did or learned in the last year, and
- do they have any personal goals for the next year?

Figure 17 presents information pertinent to answering these questions.

OVERALL RESULTS

Most adults receiving services expressed that they were proud of something they did in the last year (75.7%), and most of them indicated they had a personal goal for the next year (55.2%).

COMPARISON BY SERVICE APPROACH

Staff, or others providing supports, were more likely to believe that adults in services were proud of something or had a personal goal, if those adults were in individualized settings than if they were in community group or institutional settings. These differences were statistically significant (see column 4). However, there were no statistically significant differences in the direct responses of adults receiving services to these same questions.

COMPARISON TO THE GENERAL POPULATION

Adults in the Colorado general population were more likely to state that they were proud of something (90.7%) than were adults in services (77.5%). Likewise, adults in the general population were more likely to have a personal goal (84.2%) than were adults receiving services (55.2%). These differences were statistically significant.

Figure 17: Talents and Personal Goals

	Comparison of Service Approaches				Comparison to General Pop.		
Questions Related to Talents & Personal Goals	1993 Institutional Settings	1993 Community Group Settings (GRSS)	1993 Comm. Individualized Settings (IRSS/SL)	Significance Level	1993 Adults in General Pop.	1993 Adults In Service	Significance Level
Responses of the person in services	Col. 1	Col. 2	Col. 3	Col. 4	Col. 5	Col. 6	Col. 7
Yes, I am proud of something I did or achieved in the last year.	88.6%	96.3%	75.7%	none	90.7%	77.5%	.00001
Yes, there are some things I hope to learn or achieve in the next year...	41.3%	67.0%	58.9%	none	84.2%	55.2%	.00001
Sample Size	12	22	108		546	224	
Responses from staff or others providing support							
Yes, he/she is proud of something he/she did or achieved in the last year.	56.0%	75.5%	81.4%	.0003	NA	NA	NA
Yes, there are some things he/she hopes to learn or achieve in the next year...	25.2%	34.1%	53.9%	.00001	NA	NA	NA
Sample Size	54	136	454		NA	NA	

EXAMPLES OF THINGS TO BE PROUD OF AND PERSONAL GOALS

Adults were also asked to provide examples of what they were proud of during the last year and what their personal goals were for the next year. The following table (Figure 18) lists responses by who responded (i.e., in column 1 are adults in services who responded directly and in column 2 are others who responded for them). This table should provide a good sense of the kind of things adults with developmental disabilities learned or did during the last year of which they were proud, and also, what their personal goals are. (Note that percentages are based on those providing examples.)

The frequency with which different responses were made varied by who was being interviewed (i.e., between adults receiving services (column 1) and staff or others responding for them (column 2)). For example, looking at personal goals, staff (or other people providing supports) were much more likely to list goals of increased independence skills (51.3%) than were adults with developmental disabilities (15.3%). Instead, adults receiving services were more likely to share examples of personal goals which related to attending a special event or taking a special trip (20.8%), or learning or taking part in new recreational activities (19.4%).

Figure 18: Examples of Talents and Personal Goals

	Who Was Asked the Question	
	Adults in Service	**Staff or Others Providing Him/Her with Supports**
	Column 1	Column 2
EXAMPLES OF THINGS THAT HE/SHE DID IN THE LAST YEAR OF WHICH HE/SHE IS PROUD.		
Recreational, Hobby Or Leisure Time Skill, such as played the piano, walked for exercise, learned how to rent movies or to use the TV remote, took care of pets, was in Special Olympics, caught fish, grew a garden, learned Nintendo, how to use the radio, earned a rodeo jacket, won jackpot in Las Vegas, took a trip somewhere or a vacation	21.9%	27.7%
Work Related, got a new job, stability at the job, worked 2 jobs, better work attendance, etc.	19.0%	25.4%
Learn A New Skill Related To Upkeep Of A Home, such as picked up around the house, recycled cans, fixed things around the house, learned to cook, clean, vacuum, do windows, do yard work, or use the microwave, decorated own home, drove a lawn tractor,	12.4%	4.1%
Develop Other Independent Living Skills, such as learn to read, new speech skills, how to drive, how to use the telephone, how to type, how to tie shoes, wrote poetry, learned the alphabet, how to use the calculator, how to vote, how to operate a motorized wheelchair, learned sign language, got a People First award, did public speaking	10.5%	19.0%
Friendships and Relationships, such as went to a friend's wedding, learned to socialize better, got engaged to be married, made new friends, visited family, went home with staff on weekends, have girlfriend or boyfriend, got picture taken with a friend, developed friendship with roommate	7.6%	4.1%
Personal Change, such as lost weight or health improvement, became less forgetful, happier, sober, not setting fires, graduated from therapy, finished radiation, improved mobility	7.6%	7.3%
EXAMPLES OF PERSONAL GOALS FOR NEXT YEAR		
Attend a Special Event or Go On A Trip, such as hayride, go to Florida, Grand Canyon, concert, take an airplane ride, take a train ride, take a trip, go to circus	20.8%	10.1%
Recreational, Hobby Or Leisure Time Goal, learn to dance, new art or craft skill, learn jewelry make, take self-defense course, improve a sport or leisure skill, learn to sew, , compete at the Special Olympics, get a pet, fish, ski, be on bowling team, get a green belt, learn to play piano better	19.4%	3.6%
Work Related Goal, such as get a different job, make more money, get a child care license, learn new job skills, janitorial skills, be a weatherman, get a job promotion, get a job, increase work skills, do better on new job	16.7%	5.1%
Educational Goal, such as take a computer classes, go to the Police Academy, learn how to judge rabbits and to raise animals, take day care classes, learn better math, find finances to go to school, become an Attorney	11.1%	2.0%
Personal Improvement Goal, such as become a singer, control alcoholism, quit smoking, quit stealing, improve cleanliness, get seizures under control, get teeth fixed	2.8%	6.1%
Learn A New Skill Related To Upkeep Of A Home, such as how to cook or bake, peel apples, learn how to clean the house	2.9%	2.0%
Develop Other Independent Living Skills, such as learn to read, learn to drive, how to answer phones, learn how to write address, how to write in general, live on own in a PCA, speak out for the disabled, learn alphabet, be able to walk around the neighborhood by self, make clothing choices independently, learn to use the telephone, have more privacy and more freedom, improve financial management skills, save money, pay off debt, manage checkbook	15.3%	51.3%
Friendships and Relationships, such as improve social skills, visit parents, get married, see family more, get child back, have more friends, work on table manners, have boyfriend move in, get a boyfriend or girlfriend, want a roommate, want to live with family, make marriage work		10.7%
Obtain New Possessions, such as convertible, pet, electric wheelchair, furniture, VCR, , TV		6.1%

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Summary of Results Related to Talents and Personal Goals: Most adults receiving services said they were proud of something they achieved in the last year and had personal goals for next year. Staff, or others providing support, were more likely to believe that adults in services were proud of something or had personal goals, if these adults were in individualized settings than if they were in community group homes or institutional settings.

"Personal goals provide most people with motivation and direction. The service process should seek to understand individual goals and to support activities that will contribute to individual achievement of personal goals....Education and training should be based on personal goals."

Accreditation Council on Services for People with Disabilities, 1992

RELATIONSHIPS AND A SENSE OF BELONGING

Establishing and maintaining relationships is important to all of us. A study by Diener (1984) found that close friendships are associated with a sense of subjective well-being. Friendships are the basis for the sense of belonging we all want to feel in our personal lives, in our homes, in our work places, and in the community. "Personal relationships bring variety and richness to the lives of many people. Friends can be a significant source of comfort and support during difficult times. They can bring us companionship and share our joy in the best of times." (Accreditation Council on Services for People With Disabilities, 1992) Many sources stated that you cannot force, require or ensure that someone has friends, but you can provide opportunities, remove barriers, and respect individual preferences.

Social relationships can be at many levels of closeness, from casual to intimate, including sexual intimacy. "People with disabilities, regardless of their need for support services, should have the choice and opportunity for developing close personal relationships.... People have the right to develop and express their sexuality in a socially appropriate manner." (Accreditation Council on Services for People With Disabilities, 1992)

Relationships also contribute to personal safety. We cannot keep people safe by just visiting them annually. Instead, there is a need for regular contact with neighbors, co-workers, friends and family so that problems affecting safety are identified quickly.

People with developmental disabilities are sometimes excluded from opportunities to develop friends, are isolated socially, and are lonely. One parent stated: "What concerns us most of all is that there will be no one in our daughter's life who wants to be with her...That she will be isolated, lonely and without friends...It is our friendships that will ensure that we are a part of the community rather than just being in the community" (Coloradans for Family Support, 1990).

Colorado state law defines one goal of supports and services as to maintain relationships and to foster a sense of belonging (CRS 27-10.5-102-29). Services need to support people with developmental disabilities in making and maintaining friendships and should provide opportunities for people to find and forge friendships

The COPAR form was modified in 1993 to ask questions about friendships of persons receiving services. Since these questions are new, information is not available regarding change over time.

This section of the report will present information pertinent to answering the following questions:

- What kinds of friendships do adults in services have? For example, do they have friends other than their family or staff? Do they have close friends or romantic relationships?
- Are some service approaches more successful than others in providing opportunities for friendships and relationships?
- Do adults with developmental disabilities have the same opportunities to make friendships and a sense of community belonging as other adults in Colorado?

Figure 19 presents information pertinent to answering these questions. In the first three columns of Figure 19, the relationships of adults receiving services is compared by service approach, with the statistical significance level noted in column 4 based on the Chi Square test. In columns 5 and 6, the comparison is made between adults in services to that of other adults living in Colorado, with the statistical significance of differences noted in column 7 based on the Chi Square test. Most of the information presented within this section was collected in 1993, and the columns areheaded accordingly. However, in a few cases, the data presented

"...we have a need for belonging, love, and most of us find it among friends, family, lovers, spouses, community groups."

Norman Kunc, A Need for Belonging, TASH Newsletter, 1992

Figure 19: Relationships and a Sense of Belonging

	Comparison of Service Approaches				Comparison to General Pop.		
Questions Related to Relationships and A Sense of Belonging	**1993 Institutional Settings**	**1993 Community Group Settings (GRSS)**	**1993 Comm. Individualized Settings (IRSS/SL)**	**Significance Level**	**1993 Adults in General Pop.**	**1993 Adults in Service**	**Significance Level**
QUESTIONS ASKED OF PERSON IN SERVICE	Col. 1	Col. 2	Col. 3	Col. 4	Col. 5	Col. 6	Col. 7
Do you have friends, other than family or staff, with whom you like to do things, such as see movies, eat out, or play sports?				.05 IRSS > GRSS			.00001
Yes	57.9%	51.7%	73.8%		91.9%	66.2%	
Not sure, in between, don't know	6.2%		4.6%		1.4%	4.4%	
No, not to do things with, only family or staff	35.9%	48.3%	21.6%		6.7%	29.4%	
Not counting family or staff, do you feel extra close to any of these friends?				.0002			.00001
Yes, have some extra close friends	18.8%	58.6%	80.0%		86.7%	69.5%	
Not sure, in between, don't know	16.7%	20.3%	6.4%		1.9%	8.3%	
No, do not have close friends	64.5%	21.1%	13.6%		11.4%	22.2%	
Do you have a romantic or intimate relationship with anyone, such as a boyfriend, girlfriend, husband or wife?				none			.00001
Yes, have an intimate relationship	27.4%	29.3%	35.2%		74.5%	27.6%	
Not sure, in between, don't know		6.9%	3.9%		0.5%	5.0%	
No, do not have an intimate relationship	72.6%	64.8%	60.9%		25.0%	67.4%	
Do you feel you get along well with other people?				.02 Comm. > Institutional			.00001
Yes, generally, with most everyone	78.6%	84.3%	84.5%		98.2%	84.4%	
Not sure, in between, don't know		13.2%	11.0%		1.2%	10.7%	
No, have problems, with several people	21.4%	2.5%	4.4%		0.5%	4.9%	
Do you feel that other people like you or not?				.04 Comm. > Institutional			.00001
I am liked by most people, most of the time	72.4%	82.7%	82.3%		95.9%	82.1%	
Not sure, in between, don't know	12.6%	14.8%	15.5%		3.9%	14.1%	
Many people don't like me	15.0%	2.5%	2.2%		0.2%	3.8%	
Do you have enough friends or do you wish you had more friends? Are you lonely?				none	1992	1992	1992 .00006
Have enough friends	68.2%	73.6%	53.4%		78.5%	67.2%	
Not sure, in between, don't know	17.6%	7.1%	11.9%		5.0%	5.8%	
Do not have enough friends, lonely	14.2%	19.3%	34.7%		16.5%	27.0%	
Do you feel lonely at work, day program or school?				.04 IRSS > GRSS			.00001
No, not lonely, rarely, never	79.9%	47.7%	71.4%		89.1%	70.8%	
Not sure, in between, don't know	20.1%	22.6%	9.1%		2.1%	12.4%	
Yes, lonely		29.6%	19.5%		8.8%	16.8%	
Who decides when you can get together with your friends?				.00001	1992	1992	1992 .00001
I do	41.5%	24.8%	60.5%		66.5%	45.0%	
I do with someone else's help	33.7%	55.6%	30.0%		29.4%	36.3%	
Someone else does	24.7%	19.6%	9.5%		4.1%	18.7%	
Sample Size for Consumer Interviews	13	30	132		566	279	
QUESTIONS ASKED OF STAFF or SUPPORT PERSONS							
When he/she goes shopping, banking, and other places around town, are most people nice, pleasant, and friendly towards him/her or not?				none			.0004
Yes, generally people are nice to him/her	84.7%	85.1%	87.4%		92.9%	86.6%	
Not sure, in between, don't know	6.1%	10.9%	8.6%		4.1%	9.6%	
No, many people are not nice	9.2%	4.1%	4.0%		3.0%	3.8%	
Does he/she have any friends who are not family, not paid to work with him/her or friends who do not have disabilities?				.00001	NA		NA
Yes	28.7%	42.9%	60.6%			50.3%	
Don't know, not sure	7.9%	5.3%	8.2%			7.2%	
No	63.4%	51.8%	31.2%			42.4%	
When he/she goes shopping, banking or other places around town, are there people who recognize him/her and say "hi" to him/her and talk to him/her in passing about things other than his/her shopping business?				.00001			.00001
Yes							
Not sure, in between, don't know	35.5%	55.3%	82.2%		83.7%	69.8%	
No	13.0%	10.4%	11.7%		4.2%	11.9%	
	51.6%	34.3%	6.1%		12.0%	18.3%	
Can he/she have privacy to be alone or to be alone with guests somewhere in the home when he/she wants to be?				.00001			.00002
Yes	73.6%	83.1	94.7%		92.4%	88.4%	
Not sure, don't know	2.0%	3.1	0.1%		1.6%	1.0%	
No, there are some restrictions	24.4%	13.9	5.2%		6.0%	10.6%	
Sample Size for Staff Questions	75	170	309		566	732	

for columns 5 and 6 will be from 1992 and will be noted as such within that row.

COMPARISONS OF SERVICE APPROACHES - 1993 (Refer to Figure 19, Columns 1-4)

Three service approaches are compared in terms of their success in supporting friendships and community belonging. These three service approaches are: individualized settings (supported living or IRSS, column 3), community group homes (GRSS, column 2), and institutional settings (column 1). If the differences observed between these three service approaches are statistically significant, the significance level is noted in column 4 of Figure 19. The Social Activities already presented in Figure 7 in another section of this report are also pertinent to this goal area and are discussed here also.

- **Adults living in individualized settings participate in social activities more frequently than do adults living in community group homes or institutional settings** (see Figure 7). **This supports the move towards providing supports in more individualized settings**. This held true for 10 of the 16 social activities studied, in 4 activity areas there were no statistically significant differences.
- 60.0% of adults in individualized settings visited friends as compared to 29.7% living in group homes and 17.5% living in institutional settings. They also were more likely to have friends over to their home, to make or receive calls from friends, to correspond with friends, to attend parties outside the home, and to interact with relatives outside the home. There were only 2 areas in which community group or institutional settings showed higher activity levels than individualized settings. Both of these areas were social activities which were done in the home itself (interacting with others in your home and having a party in your home).
- **Adults living in individualized settings were more likely than adults in community group or institutional settings to respond positively to the questions asked of them about relationships**. For two of the 8 questions (having friends and not feeling lonely at work), the difference was statistically significant only for the individualized setting over the group setting (IRSS to GRSS). For 2 of the 8 questions (feel you get along well with others and that people like you), the difference was statistically significant only for community settings as compared to the institutional setting. For 2 of the 8 questions (having a close friend and deciding when to get together with friends), the difference between the individualized setting and both other settings was statistically significant. Only 2 questions of the 8 showed no statistically significant differences (having a romantic relationship and having enough friends).
- Staff or other people providing supports to people with developmental disabilities were also asked 4 questions about relationships and community belonging. **On all four questions asked of support people, adults receiving services and supports within individualized settings had the most community belonging** in terms of people recognizing them in the community and being friendly with them, also in terms of having friends (friends other than staff, family or cohorts), and in terms of being able to have privacy to be alone with guests.

"People are safer the more others care enough about their safety and well being to keep a close eye on their situation...Many people with developmental disabilities are more vulnerable exactly because they lack opportunities and assistance to make and keep good relationships."

O'Brien and O'Brien
Assistance with Integrity, 1993

SUPPORT LEVEL AND THE RELATIONSHIP INDEX - 1993
(Refer to Figure 20)

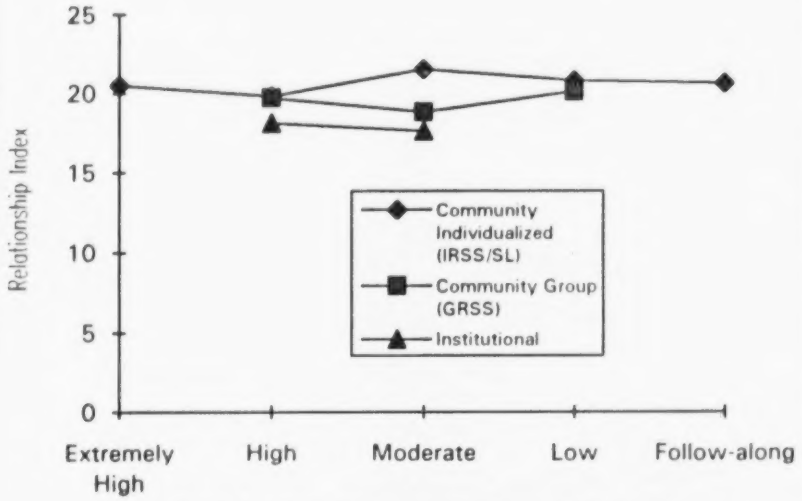
We investigated the potential that differences observed in the relationships of adults receiving residential services in institutional and community settings were more a function of the higher needs of the adults in institutional settings rather than a function of differences in service values or opportunities. A total Relationship Index was calculated by totaling the value associated with each response (3=positive, 2=in between, 1=negative) across all questions asked of both samples (general population and persons in services), with an adjustment for missing data and for questions which were not applicable to certain individuals. This total Relationship Index allows consideration of responses across all relationship questions asked in common across both samples. The higher the index value, the more evidence of establishing and maintaining relationships.

The Relationship Index was compared for each major service approach by the highest level of support required to address their needs in the areas of daily living, behavioral, mental health, medical, and legal.

Some support levels were not available to analyze for some service approaches. For example, insufficient sample sizes were available for the extremely high and low support level in the institutional settings. Follow-along support levels do not exist in the institutional settings or within community group homes.

- At the high and moderate support levels, it was found that the Relationship Index of adults receiving residential services in the community was higher than that of adults living in institutional settings. These differences were statistically significant (ANOVA, .001).
- It can also be noted that adults in community individualized settings who receive a moderate support level have a higher relationship index than do those in community group settings.
- At the high and low support levels, there was little or no difference between the Relationship Index for the two community settings (Individualized and Group).

Figure 20: Relationship Index by Support Level and Residential Setting



Highest Level of Support Needed to Address Daily Living, Behavioral, Mental Health, Medical or Legal Needs

43

SUPPORTS TO PROMOTE RELATIONSHIPS

Staff, or others providing supports, were asked what they had done in the last month to promote opportunities to make and maintain friendships and connections to the community. They provided examples such as encouraging him/her to get together with friends, helping him/her to meet new friends, encouraging him/her to spend time outside in order to meet neighbors, and assistance to participate in community events providing opportunities for socializing (church, parties, shopping, banking, camping, luncheons, clubs, taking classes like ceramics, museum, senior center, bingo, etc.).

Assistance ranged from directly accompanying him/her to the events, to helping him/her to make arrangements, to encouraging him/her to initiate such activities. Other examples of supports included: on-going counseling, a formal socialization program, peer-counseling, People's First club, assertiveness training, a letter writing program, and devices to increase communication, such as a speaker phone.

Staff providing supports within individualized settings were more likely to provide examples (85.9%) than were staff in group home (74.6%) or institutional (59.0%) settings.

Figure 21: Relationship Index by Type of Residential and Support Living Service

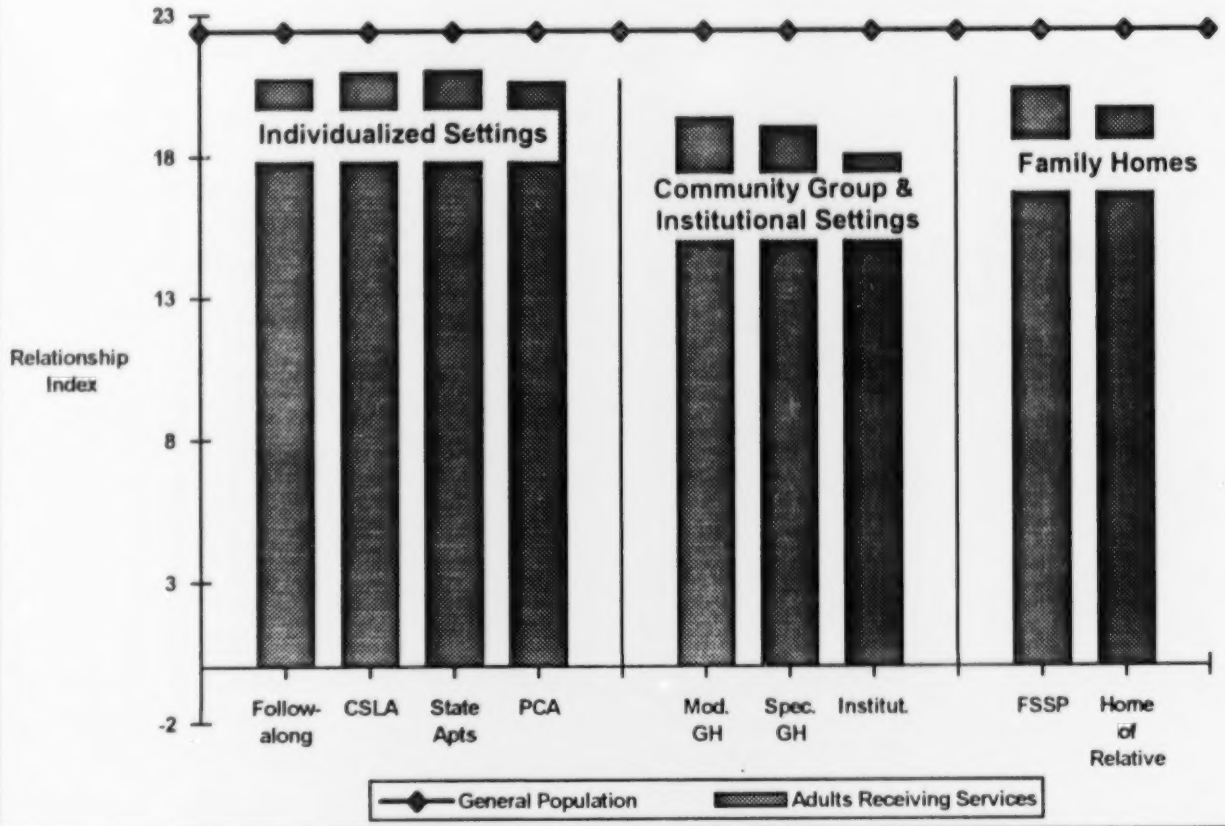


Figure 21 compares the Relationship Index for adults with developmental disabilities by the specific funding type of residential or supported service they receive, if any. (Please refer to the definitions for these service categories provided within the methodology section of this report.) The average Relationship Index value for adults in the Colorado general population is provided for comparison purposes. The purpose of this comparison was to determine which of the service types were most successful in meeting the legislative goal of helping adults to establish and maintain relationships.

The purpose of this comparison is to determine which of the residential service models is resulting in more opportunities to "maintain relationships" and "foster a sense of belonging", and which models are, therefore, more in line with the Division's statutory mission.

The following statements summarize this figure:

- All types of individualized settings provide more opportunities for relationships than do other residential settings, but the difference is not very large.
- Of all group settings, moderate group homes are doing the best job of providing opportunities for relationships and institutional settings provide the least.
- None of the current residential or supported living settings offered to adults with developmental disabilities are resulting in relationship levels similar to that of other adults in Colorado. Therefore, there are improvements to be made in all residential and supported living services.

GENERAL POPULATION COMPARISON - 1993

The relationship levels of adults in the Colorado general population can provide us with a baseline for comparing relationships of adults receiving service.

Figure 22 presents a few examples of the differences observed between relationships of adults receiving services and other adults in Colorado. Figures 7 and 19 also provide comparative information regarding the social relationships of these two groups. Other findings are summarized below:

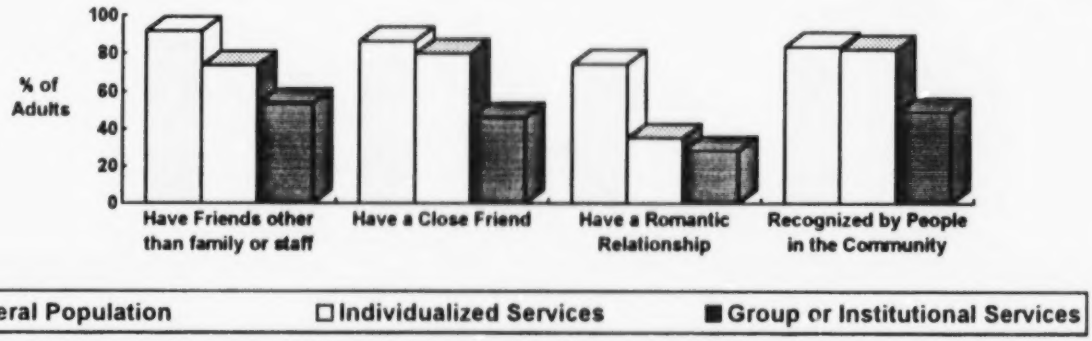
- **Adults receiving services participate in fewer social activities than do other adults in the Colorado general population** (see Figure 7, columns 5-7). These differences were statistically significant for 14 of the 16 social activities studied. Adults in the general population are more likely to have social activities including visiting with friends and relatives, calling or receiving calls from friends and relatives, corresponding with friends and relatives, and going on dates than are adults receiving services. For example, adults in the general population are twice as likely to receive calls from or to make calls to friends as adults receiving services.
- **Adults in the Colorado general population were more likely than adults receiving services to respond positively to the questions asked of them about relationships** (Figure 19, columns 5-7). This difference was statistically significant for all 11 questions asked of both groups (adults in the general population and adults receiving services). Examples of the more notable differences in the relationships of most Colorado citizens as compared to those of adults with developmental disabilities include:
  - More than 1 out of every 4 adults with developmental disabilities report NOT having any friends other than family or staff as compared to about 1 out of every 20 adults in the Colorado general population who do not have friends who are not family.
  - Twice as many adults with developmental disabilities report NOT having any close friends (22.2%) as do other adults in Colorado (11.4%).
  - 3 out of 4 adults in Colorado have a romantic relationship with someone, as compared to 1 out of 4 adults with developmental disabilities.
  - Almost twice as many adults with developmental disabilities report being lonely as do other adults in Colorado.

Summary of Findings Regarding Relationships and a Sense of Belonging: The comparison of relationships of adults with developmental disabilities to those of other adults in the Colorado general population documents the need to continue to improve opportunities for people with developmental disabilities to have social relationships.

Comparisons of major service approaches identifies that the service approach which is most successful in encouraging social relationships is individualized services.

Therefore, the Division should continue to put new resources (and to convert other existing resources) towards more individualized services and supports.

Figure 22: 1993 Comparison of Relationships for Adults in Services to Adults in the General Population



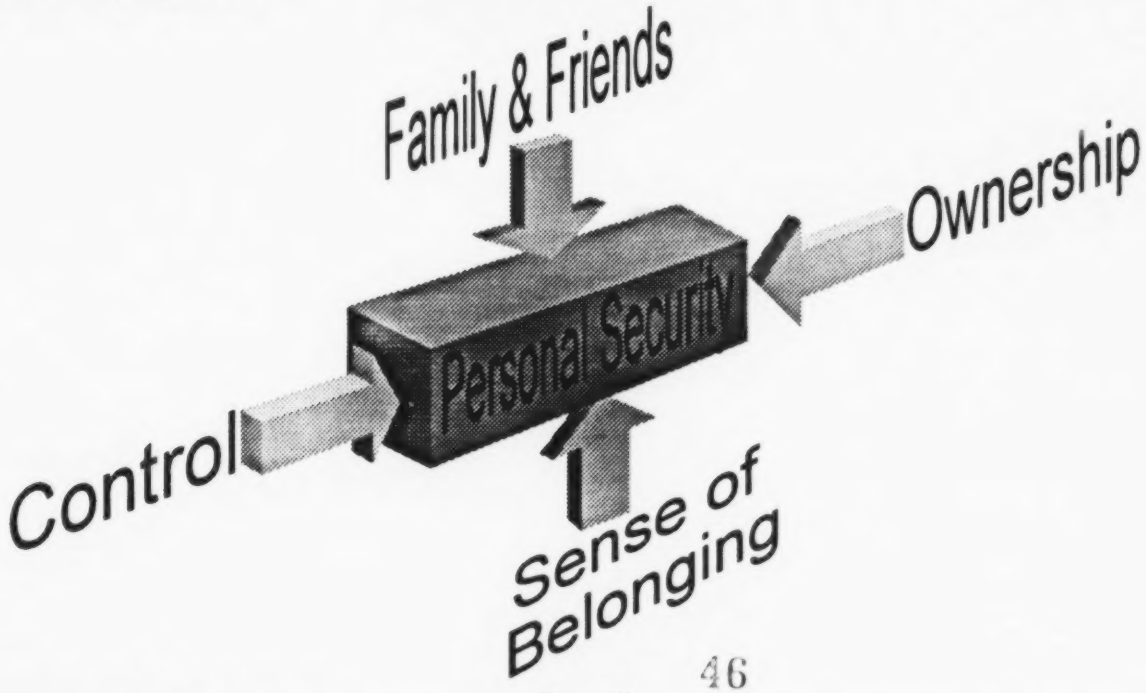
PERSONAL SECURITY

Colorado Statutes (CRS 27-10.5-102-29) state that services and supports should "enable persons with developmental disabilities to... experience personal security." John O'Brien (1991) identified several factors which affect a sense of personal security for persons with developmental disabilities, including having control over where they live and who they live with, ownership of a home, having a sense of belonging, and having supportive family and friends. The Accreditation Council on Services for People with Disabilities (1992) feel that personal security is negatively impacted when choices about where a person lives or works are outside his/her control. The new Community Supported Living Arrangement (CSLA) service also makes control of one's own home a key aspect and requires that persons in this service at least co-sign the lease or title for their home, unless they live in their family's home. During COPAR surveys, when people with developmental disabilities are asked how they like their current home, they often spontaneously express a fear that they may be moved, saying something like: "why are you asking me this - are you going to move me?"

Thus, there is strong agreement that people feel more secure when they have control over their lives and do not have to worry if the service system may choose to move them to a different home or put a different roommate in their room or home. People also feel more secure if they have friends and family to rely on and to whom they are important. Several of these aspects of personal security have been dealt with under the preceding Decision-Making and Relationship sections of this report. In those sections of this report, it was found that adults in individualized settings had more involvement in selecting their homes and their roommates, and were more likely to have community connections and friends than were adults served in community group homes or institutional settings. These findings would support a conclusion that adults living in individualized settings experience more personal security.

"What matters most to people's safety is the extent and quality of their relationships."

O'Brien and O'Brien
Assistance with Integrity, 1993



This section of the report will look at two additional aspects of personal security:

- Does the person feel safe in his/her home and, if not, why?
- Does the person own or sign the lease for his/her home?

Figure 23 presents information pertinent to answering these questions. In the first three columns of Figure 23, responses for adults receiving services are compared by service approach, with the statistical significance level noted in column 4 based on the Chi Square test. In columns 5 and 6, the comparison is made between adults in services to that of other adults living in Colorado, with the statistical significance of differences noted in column 7 based on the Chi Square test.

The findings are summarized below.

- Most adults receiving services responded that they feel safe in their home (92% overall, 75.6% to 100% dependent on setting).
- Only 10 adults in services listed any reasons why they did not feel safe in their home. The reasons mentioned included fear of someone breaking into the home, afraid of other persons living in the home, lack of a security lock on the door, having been robbed before, and alarms which keep going off.
- Only 2 adults in the general population indicated any reasons why they did not feel safe in their home, these were fear of someone breaking into the home and concern about people taking things without asking first.
- While most adults receiving services feel safe, they may not necessarily feel secure, if having control of the rental lease or home title is any indication. Only 16.5% of adults receiving services either sign or co-sign the lease/title of the home they live in as compared to 88.2% of adults in the general population.
- However, nearly 1 out of every 3 adults in individualized services (31.0%) either signed or co-signed the lease/title of their home as compared to 1 out of every 76 adults in community group homes (1.3%) co-signing the lease/title of their home.

Summary of Findings Related to Personal Security: The sense of personal security is inter-related with several other mission-critical factors, including strong relationships, community connections, and decision-making involvement. Therefore, improvements in these other factors should also increase personal security. Supports in individualized settings demonstrated better outcomes in several factors related to personal security than did group settings, including relationships, decision-making areas related to personal security (involvement in selecting a home and roommates), and signing the title or mortgage lease.

Figure 23: Personal Security - Two Factors

	Comparison of Service Approaches				Comparison to General Pop.		
Questions Related to Personal Security	**1993 Institutional Settings**	**1993 Community Group Settings (GRSS)**	**1993 Comm. Individualized Settings (IRSS/SL)**	**Significance Level**	**1993 Adults in General Pop.**	**1993 Adults in Service**	**Significance Level**
	Col. 1	Col. 2	Col. 3	Col. 4	Col. 5	Col. 6	Col. 7
Do you feel safe in your home?				.03			.004
Yes, I feel pretty safe	100.0%	75.6%	91.5%	IRSS >	96.1%	92.0%	
In between, no sure, don't know		10.6%	2.3%	GRSS	2.5%	2.6%	
No, not at night, not in my yard, not when I'm alone, etc.		13.9%	6.2%	only	1.4%	5.4%	
Sample Size	13	32	132		566	282	
Who signed the rental lease or title/mortgage papers for the apartment or home where he/she lives?				.00001			.00001
He/She did			11.2%		32.0%	6.1%	
He/She did jointly with spouse or housemate		0.2%	4.9%		55.7%	2.7%	
He/She did with parent or agency co-sign		1.1%	14.9%		0.5%	7.7%	
Parent/relative/guardian did	17.2%	0.3%	4.2%		7.4%	24.2%	
Agency did	62.7%	96.2%	35.7%			44.6%	
Other	20.1%	2.1%	29.1%		4.4%	14.7%	
Sample Size	67	142	230		566	735	

SELF-RESPECT

One of the legislatively mandated goals for the Division is to provide services and supports which promote the self-respect of persons with developmental disabilities (CRS 27-10.5-102-29). Self-respect is the degree to which a person sees value in himself or herself. Several studies have identified self-esteem as a very important consideration in determining quality of life or life satisfaction (Campbell, Converse and Rodgers, 1976; Diener, 1984; Andrews and Withey, 1976). Self-respect is alternately referred to as self-esteem self-concept, and self-worth.

Coopersmith (1967) relates self-respect to how an individual is treated by others and their history of success in the world. Littlejohns, O'Flaherty, and Bolton (1988) suggest that personal worries of people with developmental disabilities need to be identified and that if those worries can be overcome, then feelings of self-esteem would increase. Kunc (1992) states that self-worth comes from community and belonging, that you have to be valued as a person to have a high self-esteem. He sees one of the very most damaging things to people's self-esteem is keeping them separated and isolated the community. The Accreditation Council on Services for People with Disabilities (1992) also identify having valued social roles as being important to self-esteem. From these viewpoints, it would follow that self-esteem is linked closely to other factors already discussed within this report, such as developing friendships, community inclusion, personal security, having a job or other valued role, etc.

Several questions were added to the COPAR survey in 1993 in an attempt to measure self-esteem. These were questions identified on other tools and in other states as being related to self-esteem. However, it is widely recognized that self-esteem is a difficult concept to measure. Balla and Zigler (1979) indicate that there are almost as many measures of self-respect as there are studies of self-respect of people with developmental disabilities. Responses to self-esteem questions can be impacted by people's ability to recognize the purpose of the question and the resulting tendency to keep feelings of low self-worth private. There also can be some variation in feelings of self-worth dependent on recent events. When asked about measuring self-esteem, Colleen Wieck (Governor's Planning Council on Developmental Disabilities) said "it's as variable as the day you ask." (as quoted within Allen, Shea & Associates, 1992) Likewise, Robert Gettings (Director of the National Association of State Developmental Disabilities Program Directors) was quoted as saying "How I feel about myself depends on when you ask me." To try to address variability of self-reported self-esteem, the COPAR study included one question asked of staff (or other persons providing support) regarding their impression of the person's self-esteem. It is believed that people generally form a fairly stable opinion of other people's feeling of self-esteem, based on the way those people talk about themselves, interact with others, etc. Therefore, this is probably a more stable, though indirect, measure of self-esteem.

Figure 24 summarizes responses to these questions (note this figure is continued on two pages). In the first three columns of Figure 24, the responses of adults receiving services is compared by service approach, with the statistical significance level noted in column 4 based on the Chi Square test. In columns 5 and 6, the comparison is made between adults in services to that of other adults living in Colorado, with the statistical significance of differences noted in column 7 based on the Chi Square test.

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OVERALL RESULTS - 1993
(Refer to Figure 24, Column 6.)

On the positive side,

- **Staff believe that most people receiving services (55.7%) have a high self-esteem. However, staff also believe that about 1/3 of all adults in services have a low self-esteem.**
- **Most adults receiving services:**
  - felt in control of their life (74.4%),
  - got lots of enjoyment out of life (55.6%),
  - said they were proud of themselves (85.7%),
  - felt they got along well with other people (84.4%),
  - felt that other people like them (82.1%),
  - did not feel they were being bossed around too much (62.9%),
  - felt their job was important (91.4%),
  - did not feel left out of things at work (69.5%),
  - felt their job was challenging enough (57.1%), and
  - felt they had enough things to do around the home (68.6%).

Figure 24: Responses Indicative of Self-Esteem (note that this table is continued to the next page)

	Comparison of Service Approaches				Comparison to General Pop.		
Questions Related to Self-Respect	**1993 Institutional Settings**	**1993 Community GRSS Settings**	**1993 Comm. IRSS or Supported Living Settings**	**Significance Level**	**1993 Adults in General Pop.**	**1993 Adults in Service**	**Significance Level**
	Col. 1	Col. 2	Col. 3	Col. 4	Col. 5	Col. 6	Col. 7
Staff were asked...Do you think this person has a high self-esteem or not so high? How good do you think he/she feels about himself/herself?				.00001	NA		NA
My impression is that he/she has a high or fairly high self-esteem	44.3%	46.6%	56.9%			55.7%	
I have no impression, don't know	27.6%	20.9%	7.8%			12.8%	
My impression is that his/her self-esteem is low or is not so high	28.1%	32.5%	35.3%			31.6%	
Sample Size	75	170	309			740	
Questions asked of Adults Receiving Services							
Do you feel in control of your life?				none			.00001
Yes, I feel in control of my life	60.0%	56.1%	78.1%		90.3%	74.4%	
In between, not sure, don't know	18.8%	32.1%	14.9%		6.5%	17.1%	
No, I feel out of control, someone else seems to control, or life circumstances seem to control my life	21.2%	11.8%	7.0%		3.2%	8.5%	
Overall, would you say life...				none			.00001
Brings out the best in you.	41.2%	58.7%	41.9%		48.8%	47.5%	
Treats you like everybody else	43.5%	39.1%	50.0%		49.8%	43.7%	
Doesn't give you much of a chance	15.3%	2.2%	8.1%		1.4%	8.7%	
How much enjoyment and satisfaction do you get out of life?				none			.00001
Lots of enjoyment	43.6%	50.5%	54.6%		81.6%	55.6%	
Some, In between, not sure, don't know	28.1%	34.4%	30.7%		17.3%	28.8%	
Not much	28.3%	15.0%	14.6%		1.1%	15.6%	
Would you rate your life as...				none			.00001
Better than most	51.8%	19.2%	30.1%		51.6%	34.1%	
About average	26.3%	65.4%	58.1%		47.3%	55.8%	
Worse than most	21.9%	15.4%	11.8%		1.1%	10.1%	
How often do you worry about what other people expect of you...				none			.001
Rarely	22.4%	15.0%	21.3%		36.2%	21.2%	
Sometimes	59.8%	65.0%	49.3%		36.6%	47.7%	
Often	17.8%	20.0%	29.4%		27.2%	31.1%	
Are you proud of yourself?				none			.0007
Yes, often proud, sometimes, mostly	100.0%	98.4%	94.4%		92.6%	85.7%	
In between, not sure, don't know		1.6%	4.3%		5.8%	11.3%	
No, not proud, not lately			1.3%		1.6%	3.0%	
How are things going in your life? Would you say that things in your life...				none			none
Are going great	33.3%	38.1%	43.8%		52.5%	48.0%	
In between, not sure, don't know	54.4%	58.4%	49.7%		44.5%	47.6%	
Not so well	12.3%	3.5%	6.4%		3.0%	4.5%	

On the concerning side, about 1 out of every 4 adults in services feels he/she is bossed around too much at work or home, feels what he/she does at work is boring, often worries about what others think of him/her, and is bored at home. Nearly 1 out of every 10 adults in services feels that life does not give him/her much of a chance, does not get much enjoyment out of life, rates his/her life as worse than most, does not feel in control of his/her life, and feels left out of things at work.

COMPARISONS OF SERVICE APPROACHES - 1993 (Refer to Figure 24, Columns 1-4)

Three service approaches are compared in terms of their success in enhancing self-esteem. These three service approaches are: individualized settings (supported living or IRSS, column 3), community group homes (GRSS, column 2), and institutional settings (column 1). When the differences observed between these three service approaches are statistically significant, the significance level is noted in column 4 of Figure 24. The findings are summarized below.

- **For most measures, responses across service approaches did not vary significantly.** (I.e., 13 of the 16 measures had no statistically significant differences by approach.)

Figure 24: Responses Indicative of Self-Esteem, continued

	Comparison of Service Approaches				Comparison to General Pop.		
Questions Related to Self-Respect	**1993 Institutional Settings**	**1993 Community Group Settings (GRSS)**	**1993 Comm. Individualized Settings (IRSS/SL)**	**Significance Level**	**1993 Adults in General Pop.**	**1993 Adults in Service**	**Significance Level**
Questions asked of Adults Receiving Services	Col. 1	Col. 2	Col. 3	Col. 4	Col. 5	Col. 6	Col. 7
Do you feel you get along well with other people?				.02			.00001
Yes, generally, with most everyone	78.6%	84.3%	84.5%	Comm. >	98.2%	84.4%	
In between, not sure, don't know		13.2%	11.0%	Insti-	1.2%	10.7%	
No, have problems, with several people	21.4%	2.5%	4.4%	tutional	0.5%	4.9%	
Do you feel that other people like you or not?				.04			.00001
I am liked by most people, most of the time	72.4%	82.7%	82.3%	Comm. >	95.9%	82.1%	
In between, not sure, don't know	12.6%	14.8%	15.5%	Insti-	3.9%	14.1%	
Many people don't like me	15.0%	2.5%	2.2%	tutional	0.2%	3.8%	
Do people at your home or work tell you what to do too often? Boss you around too much?				none			.00001
No, people do not boss me	81.1%	44.7%	59.7%		86.9%	62.9%	
In between, not sure, don't know		8.8%	14.9%		3.0%	11.0%	
Yes, people boss me around	18.9%	46.5%	25.4%		10.1%	26.1%	
If people are bossy, where is that, at home, work or both?				.002			none
Home	47.0%	86.0%	22.0%		29.5%	34.2%	
Work	36.2%	9.7%	66.7%		52.5%	57.2%	
Both	16.8%	4.3%	11.3%		18.0%^	8.6%	
Do you feel your job, day program or school is important to yourself or to others?				none			.00001
Yes, its important to me, to others, both	100%	99.0%	91.3%		98.4%	91.4%	
In between, not sure, don't know			7.2%		0.2%	6.8%	
No, not very important		1.0%	1.6%		1.4%	1.8%	
Do you feel left out of things at work, day program or school?				.01			.00001
No, never, rarely	94.9%	48.6%	72.6%	IRSS >	76.9%	69.5%	
In between, not sure, don't know		35.6%	13.4%	GRSS	2.6%	16.2%	
Yes, I feel left out sometimes, many times	5.1%	15.8%	14.0%		20.5%	14.3%	
Do you feel the things you do at work, day program, or school are boring, do you need more challenge?				none			.002
No, rarely, never	33.3%	27.2%	56.6%		63.9%	57.1%	
In between, not sure, don't know	7.3%	27.7%	14.7%		8.9%	17.9%	
Yes, boring, often	59.4%	45.1%	28.7%		27.3%	25.0%	
Do you have enough things to do around home during your spare time or do you get bored at home?				none			.00001
Enough things to do	69.1%	58.5%	61.3%		90.3%	68.6%	
In between, not sure, don't know	6.2%	7.2%	12.0%		2.7%	8.2%	
Bored, not enough things to do	24.7%	34.3%	26.7%		7.1%	23.2%	
Sample Size	13	31	132		566	280	

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- **Staff, and others providing supports, were more likely to identify adults in individualized settings as having a high self-esteem than they did for adults served in community group homes or institutional settings.** This finding was statistically significant.
- **Adults living in institutions were more likely to feel that other people do NOT like them** (15.0%) than were adults living in community settings (2.2-2.5%). This finding was statistically significant.
- **Adults living in institutional settings were more likely to report that they have problems getting along with other people** (21.4%) than were adults living in community settings (2.5-4.4%). This finding was statistically significant.

GENERAL POPULATION COMPARISON - 1993 (Refer to Figure 24, columns 5-7)

The responses of adults in the Colorado general population can provide us with a baseline or a performance goal for services for adults with developmental disabilities. When the differences noted between the Adults in Service and the General Population column are statistically significant, the significance level of that difference is noted in column 7 for Figure 24.

- **The general population was more likely to respond positively to 13 of the 15 questions than were adults receiving services.** The only questions which did not show a statistically significant difference were "how are things going in your life" and the "location where people are bossy".
- Some of the more interesting differences are noted below:
  - **Adults receiving services were more than twice as likely to feel they are bossed around too much than were other adults in Colorado.**
  - **Adults receiving services were ten times more likely than were other adults in Colorado to say that their life is worse than most people's or that they do not get much enjoyment out of life.**

"Roles are given various levels of status by society...people increase their status when they fulfill the roles of the team athlete, church member, or county arts council volunteer...The roles we fill in life (child, parent, spouse, worker, volunteer, etc.) express what is important to us and define our expectation for ourselves."

Accreditation Council on Services for People with Disabilities, 1992

INDIVIDUAL RESIDENTIAL AND SUPPORTED LIVING SERVICE MODELS - 1993

A Self-Respect Index was calculated by summing the value associated with responses to each of the questions in Figure 24 (with 3=a positive response, 2=an in-between or neutral response, and 1=a negative response), with an adjustment for missing data. A higher score on this index is considered to be indicative of higher self-esteem.

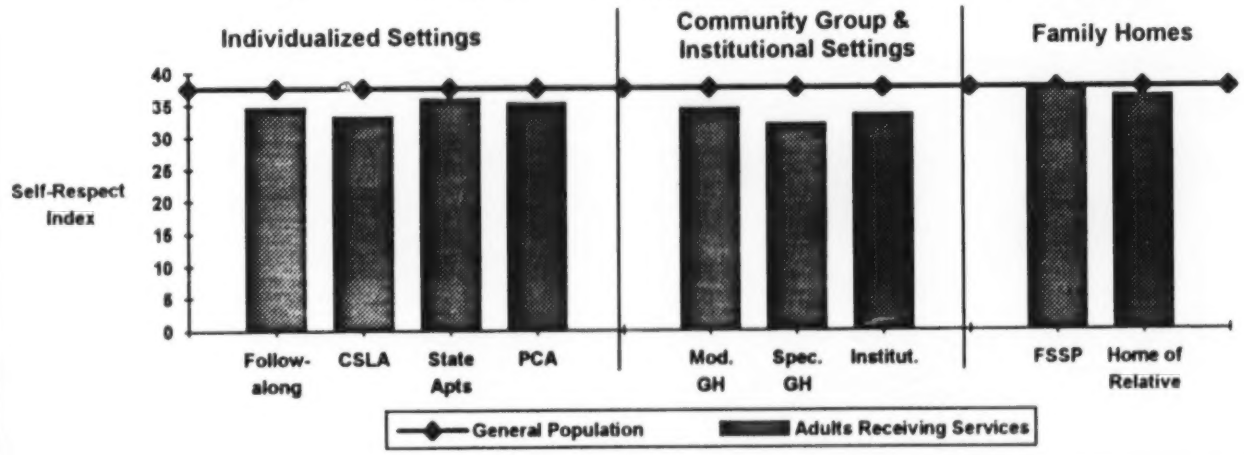
Figure 25 compares this Self-Respect Index for adults with developmental disabilities by the specific funding type of residential or supported service they receive, if any. (Refer to the Program Evaluation Methodology section earlier in this report for a definition of the service categories.) The average Self-Respect Index value for adults in the Colorado general population is provided for comparison purposes.

The purpose of this comparison is to determine if any of the residential or supported living service models are resulting in greater self-esteem and which models, if any, are therefore more in line with the Division's mission to improve self-respect.

The following statements summarize this figure:

- Adults living in their parent or relative's home and receiving supports (FSSP) had the same self-esteem index score as did other adults in the general population. Next highest were adults living in their parent or relative's home without support and those living in state-funded apartments.
- The average self-esteem index scores were similar across all residential and supported-living service approaches.

Figure 25: Self-Respect Index by Type of Residential or Support Living Service



HOW DOES SELF-RESPECT RELATE TO OTHER MISSION-CRITICAL FACTORS

Discriminant analysis is a statistical approach which seeks to identify those factors which can be used to best predict the value of another factor. Discriminant analysis was run in an attempt to determine what factors relate best to staff's impression of the self-esteem of persons in service. The results of this analysis showed that five questions asked of adults in services had a statistically significant relationship to staff's impression of self-esteem. These five questions were:

- How much enjoyment and satisfaction do you get out of life? (Satisfaction) (Discriminant Analysis, .0003)
- Overall, would you say life: brings out the best in you, treats you like everybody else, or doesn't give you much of a chance? (Discriminant Analysis, .0001)
- Do you feel that other people like you or not? (Relationships) (Discriminant Analysis, .0001)
- Do people at your home or work tell you what to do too often? Boss you around too much? (Decision-making) (Discriminant Analysis, .0001)
- Do you have enough things to do around home during your spare time or do you get bored? (Leisure, Inclusion in Community Life) (Discriminant Analysis, .0001)

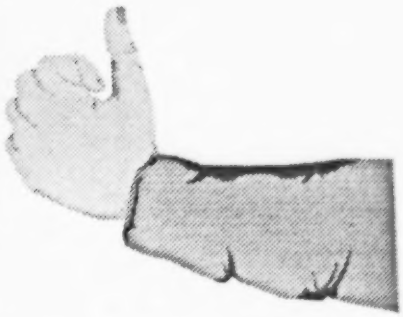
It is important to note that four of the five factors which had a statistically significant relationship to self-respect, are also closely related to other major mission-critical factors: Satisfaction, Relationships, Decision-Making, and Inclusion in Community Life.

Summary of Findings Regarding Self-Respect: Self-esteem is closely related to other legislative goals of services for people with developmental disabilities, including improved relationships, decision-making, inclusion, and satisfaction. Therefore, it is predicted that self-respect will increase as the Division and the service system work towards improving the outcomes in these other areas.

"What we have forgotten in our society is that self-worth can never be created apart from community. What we have forgotten is that community and belonging are prerequisites for self-esteem...Most of our self-doubt and self-hatred dissipates when we are in an environment where we feel welcome and valued."

Kunc, A Need for Belonging, TASH Newsletter, 1992.

COLORADO CITIZENS' AGREEMENT WITH SERVICE VALUES



While the primary purpose of the general population survey was to obtain baseline statistics for comparison with adults receiving services, the opportunity was also taken to investigate whether or not Colorado citizens were in agreement with many of the service philosophies of the Division and those embodied in state legislation.

We were pleased to find that most Colorado citizens were in agreement with our service values (Figure 26, see column 1 where strongly agree and agree a little responses were combined). Of the 1000 adults surveyed from the Colorado general population, 90% or more agreed with all of the service philosophies presented. From 70% to 87% of them agreed **strongly** with these philosophies. Only a very small percentage of adults in Colorado were in disagreement with these philosophies (from 1.0 to 2.2% disagreed either a little or strongly).

DEMOGRAPHICS

The amount of agreement with Division values was studied relative to other factors, including: (1) whether they knew someone with developmental disabilities, (2) whether they themselves had a disability, (3) their minority status, (4) their gender, (5) their marital status, (6) whether they had children, and (7) their employment status. Only four statistically significant differences were noted.

Adults who interact with individuals having developmental disabilities were slightly more likely to agree with their right to have a choice of neighborhoods to live in (98.3%) than were persons not having interactions (94.7%), (Chi Square, .006).

Adults in the general population who said that they did not have a disability were slightly more likely to agree with community integration (97.7%) than were adults in the general population who said that they did have a disability (94.5%), (Chi Square, .006).

Adults who were not working were less likely than adults who were working to agree with community integrated activities (94.9% vs. 98.4%), choice to live with family or alone (86% vs. 92%), and the right of adults with developmental disabilities to choose a neighborhood in which to live (94.6% vs. 98.0%)(Chi Square, .0007, .01, .0009, respectively).

Minority status, gender, marital status, and whether or not they had children had no impact on their agreement with service philosophies.

COMMENTS AND CLARIFICATION

Many of the adults who were surveyed provided clarification of their opinions. The most frequently made comments are provided below with the number of respondents making those comments listed in parentheses.

- Regarding decision-making, the most frequent remark was that they should be making choices if they are capable (108 respondents). Other comments included: that guidance may need to be available (30), and that safety issues need to be addressed, such as nutrition, safeguarding them from being taken advantage of by others (10).
- Regarding community connections, the most prevalent qualification was again "dependent on the capability of the person" (13 respondents). Other comments included: concern if someone is known to be dangerous (2), concern that society may be cruel (2), and concern that supervision needs be addressed (2).
- The most frequent comment provided regarding community inclusion was again that it depends on the capabilities of the individual (45 respondents). Additional comments were: that supervision was needed (7), concern for the safety of the person with a disability and the safety of others (4), and concerns about costs (3).
- In response to the "right to live in any neighborhood" question, there were very few qualifications made. The comments were: dependent on the person's capability or degree of disability (14), they have the right to live wherever they want (6), supervision may be needed (5), "any neighborhood" should not include a neighborhood with high crime rates due to safety (3), and within funding (3).

Figure 26 Colorado Citizens Express Their Agreement With Service Philosophies

Service Philosophies (note that boldfaced titles were added for easy reference on this table and were not part of the survey)	**Agree (Strongly + a little)**	**Strongly Agree**	**Agree a little**	**Neutral**	**Disagree a little**	**Strongly Disagree**
	Col. 1	Col. 2	Col. 3	Col. 4	Col. 5	Col. 6
Have Choices: I believe persons with developmental disabilities should, to the greatest extent possible, have choices and make decisions about their own lives, such as choosing what clothes to wear, what groceries to buy, how to spend their spare time, how to spend their personal money, etc.	94.3%	74.9%	19.4%	4.8%	0.9%	0.1%
Community Connections: I believe persons with developmental disabilities should have opportunities to meet and make friends with their co-workers, neighbors, and other persons they meet in their daily lives as opposed to solely interacting with family, other persons with developmental disabilities, or persons paid to provide them with services.	97.3%	87.3%	10.0%	1.9%	0.5%	0.3%
Community Inclusion: I believe opportunities and supports should be provided to persons with developmental disabilities to enable them to participate in the same types of activities and in the same places as other persons in Colorado, such as shopping at local grocery stores, eating at restaurants, using public schools, libraries, and parks.	96.1%	82.9%	13.2%	2.8%	0.8%	0.3%
Right to Choose Where to Live: I believe any person with developmental disabilities should be able to live in any neighborhood he/she chooses, including my neighborhood, given appropriate services, supports and supervision. *(in the same type home or apartment as currently exists in your neighborhood and with appropriate supervision and assistance. We are talking about all levels of developmental disabilities, including related medical or behavior issues.)*	96.9%	86.2%	10.7%	1.8%	0.6%	0.7%
Supported Employment in the Community: I believe employment services for persons with developmental disabilities should provide opportunities and supports to work in real jobs in the community. *(versus working in segregated settings with other persons with developmental disabilities. Employment services means help finding jobs, job training and supports on the job.)*	95.7%	82.7%	13.0%	2.7%	0.9%	0.6%
Services That Let Children Stay with Their Families: I believe services to families having children with developmental disabilities should enable the child to remain with their family rather than separating them from their family.	90.4%	77.1%	13.3%	7.4%	1.5%	0.7%
Serve Adults in the Community not in Institutions: I believe services should also enable adults with developmental disabilities to either remain with their families or to live separately in their own homes, rather than to live in large segregated institutions.	90.2%	69.6%	20.6%	8.4%	1.2%	0.2%

- When responding to the question about providing opportunities to work at real jobs in the community, respondents commented: if the person is qualified and capable of doing the job (47), there should not be a hiring quota (2), and they should not be selected over more qualified applicants (2).
- When responding to the question on whether supports should be provided to enable a child to remain with their families, the most common concerns were: the severity level of the child's handicap (38 respondents), the competence of the family (37), that it should be the family's decision (23), and that appropriate services should be available to assist the family (6).
- Regarding whether adults should have a choice to live in their own home or with parents, rather than in institutions, comments included: dependent on the severity of the disability (41 respondents), the capability of the person to take care of themselves (32), family and person's choice (19), and adequacy of support (3).

INTERACTIONS WITH PEOPLE WITH DEVELOPMENTAL DISABILITIES

Adults in the Colorado general population were also asked what interaction, if any, did they have with persons with developmental disabilities. Sixty percent (60%) of the adults in the general population survey report having some level of interaction with persons with developmental disabilities and an additional 14% indicated they knew of someone with a developmental disability, but had no interaction with him/her.

The types and frequencies of interactions included:

- 19% have a family member with a developmental disability.
- 27% have a friend who has a developmental disability.
- 12% interact with a co-worker or classmate with a developmental disability.
- 14% interact during breaks or meals at school or work with a person having a developmental disability.
- 22% have social interactions with a person having a developmental disability, such as going to office parties, sports events, etc.
- 6% interact when commuting to and from work or school with a person having a developmental disability.
- 20% indicated they had other types of interactions with persons with developmental disabilities than those listed above.

Summary of Findings about Citizens' Agreement with Service Values: Colorado citizens expressed a high degree of agreement with the service philosophies that guide the Division and its service organizations.

Direct quotes from Colorado citizens:

"I believe they should work at regular jobs like anyone else."

"If they are capable, let them do it. Let them be as independent as they can possibly be."

"Why shouldn't they be able to? They pay taxes too!"

"They should have choice and services available to make that choice."

"Most would learn more if they could do it themselves."

"Everyone should be able to live where they want. I don't believe in keeping anyone out."

"I feel, if they can do the job, they should be hired."

"People that complain about retarded persons moving into their neighborhood really 'chap me', make me mad."

"The more normal mentally retarded people are treated, the more normal they become and the more able to be integrated."

COPAR General Population Survey, excerpted from Ruth and Struxness, Fall, 1993 Director's Report.

SUMMARY OF SERVICE OUTCOMES

"In many states, people with disabilities are living in their own homes in the community with one or two friends of their choices through the assistance of support services targeted to their specific needs. As this happens, the individuals enjoy increased independence and sense of competence; improved relationships with family members and friends; and increased respect, dignity, and feeling of being a part of community life."

Wright and King, National Conference of State Legislatures, February, 1991

Analysis of COPAR information supports that individuals with developmental disabilities in Colorado are benefiting from services.

- Adults with developmental disabilities are benefiting from the services being delivered to them in terms of demonstrated total system-wide growth in decision making, community inclusion, and community integrated employment.
- 60.2% to 92.3% of adults receiving services are satisfied with services in the eighteen factors surveyed.
- Most adults receiving services expressed that they were proud of something they did in the last year (75.7%), and most of them indicated they had a personal goal for the next year (58.9%).

Analysis of COPAR data has also supported the directions being taken in service delivery by indicating that newer service models in which individualized residential and supported living services provided in small settings of 1-3 adults have advantages over services offered via the older service models of community group homes or institutional residences.

- A greater percentage of adults supported in individualized settings had involvement in decision making than did those residing in community group or institutional settings in all 15 of the decision areas studied. This finding held true regardless of support level needs.
- Adults receiving supports in individualized settings in the community participated in an average of 22 different activities as opposed to an average of 19 for adults in community group homes and 13 for adults in institutional settings. This finding held true regardless of support level needs.
- Adults served in individualized settings were more likely to have friends and respond positively to other questions about relationships than were adults served in community group or institutional settings.
- Staff, and others providing supports, were more likely to identify adults in individualized settings as having a high self-esteem than they were for adults served in community group homes or institutional settings.
- Staff, and others providing supports, were more likely to believe that adults in services were proud of something or had a personal goal if those adults were in individualized settings than if they were in community group homes, or institutional settings.
- Findings also indicate that Colorado citizens are in substantial agreement with the service philosophies of the Division for Developmental Disabilities.
- Adults receiving individualized supports in community settings have a quality of life which is closer to adults in the Colorado general population than is true for adults receiving services in community group home or institutional settings.

Analysis of this COPAR data has also indicated areas in which additional improvements are still needed.

- Findings indicate that most adult citizens in Colorado's general population participate in more activities, have more involvement in making decisions that affect their lives, and feel better about their social relationships than do adults receiving services.
- Adults receiving services are less likely to be proud of something they did in the last year or to have personal goals for next year than are other adults in Colorado. Adults receiving services also have a lower self-esteem than do other adults in Colorado.
- The two most notable differences in satisfaction were that adults with developmental disabilities are more likely to express loneliness and are less likely to say they are happy than are other adults in Colorado.

CONCLUSION

Analysis of outcome information supports Colorado's efforts to concentrate new resources and to convert existing resources towards more individualized residential, work, and supported living settings. These settings have been demonstrated to result in outcomes which are closely aligned with the legislative mandate to enable persons with developmental disabilities to make increasingly responsible choices, to exert greater control over their lives, experience presence and inclusion in their communities, develop their competencies and talents, maintain relationships, foster a sense of belonging, and to experience personal security and self-respect.

RECOMMENDATION

Colorado should continue to allocate new resources towards smaller, individualized community residential, work, and supported living settings and, as opportunities arise, Colorado should convert resources currently directed toward other less successful service approaches to these more successful individualized programs.

"In an era of tightening budget restrictions, states should not continue to spend a large proportion of their budgets on institutional care or large congregate care when virtually all major studies show that people are better off in typical community residences, given the proper supports."

Wright and King, National Conference of State Legislatures, February, 1991

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